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editorial

Testing times for DLA

There are many reasons why medicalising entitlement to Disability Living Allowance (DLA) is wrong.

For one thing, while medical verification of impairment has always been a requirement, the benefit itself was never and is not intended to meet the medicalised costs of being disabled. Most of the things which result in additional cost for us are nothing to do with our medical conditions.

“The other assumption which underpins the decision to introduce medical assessments is that disability is a question of degree”

Take transport. Disabled people are more likely to have to take taxis from A to B, not primarily because medical symptoms rule public transport out as an option, but because many buses and trains are not accessible; or for people in rural areas, they're not only inaccessible, but infrequent. If you have to attend an appointment – even if that

appointment is with your GP (which is not to say it has anything to do with your impairment anyway) – how can you rely on a bus service to get you there if the buses run only a few times a week?

For the same reasons, or for others related to the accessibility of supermarkets, you may opt to use an online shopping service. Here again, it's not necessarily the presence of an impairment which governs such a decision but you will be required to pay the additional cost of having the weekly shop delivered to your door.

The other assumption which underpins the decision to introduce medical assessments is that disability is a question of degree. That there is some point on the impairment continuum where you are more or less severely disabled. Even if that's true – and life may well be tougher for a totally blind person or a wheelchair-user than it is for me, with my small amount of sight and the ability to walk – the degree lies not with our comparative impairments, but with the extent to which society's barriers disable us all.

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newsview

Begg blasts benefits cuts agenda

Ian Macrae

Iain Duncan Smith's appointment as Secretary of State for Work and Pensions in the new coalition Government was seen by many as a shoo-in.

Needing to revive a political career dealt a potentially fatal blow by his drumming out as Tory party leader in 2003, he had, it was felt, established something of a track record with the Work and Pensions brief through the work of his policy think-tank, the Centre for Social Justice (CSJ).

But Labour MP Anne Begg is unconvinced. No slouch in this particular policy area herself, she's spent nine of her 13 years in parliament serving on the Parliamentary Select Committee for Work and Pensions and has recently been elected its chair.

She makes no attempt to conceal her scepticism.

"I keep reading about all the work he'd done getting people off benefit. Now, he hadn't done anything about getting people off benefit. He'd written a couple of pamphlets and things [actually two CSJ reports on back-to-work welfare reform]. He'd visited Easterhouse in Glasgow.



Begging to differ: new Select Committee chair Anne Begg

But one visit to a sink estate in Glasgow a policy does not make."

And she's concerned about the apparent willingness of people to assume that IDS has wisdom and knowledge in the area of welfare and benefit reform.

"We don't know whether

he knows about welfare reform. One of the things we've learned over the last 13 years in government is that it's an incredibly complex policy area.

"But there's also the law of unintended consequences. So what might seem a good policy on paper and with all

the right rhetoric behind it, can go pear-shaped and, once it's implemented, can achieve the very opposite effect."

Judging by the new Government's performance so far, she believes that they've a lot to prove. Responding to an announcement by Chancellor George Osborne that the Government intends to speed up the rate at which people are assessed for Incapacity Benefit and thereby increase the numbers who come off benefit and go back to work, Anne Begg said: "My concern is that it's being done on a cuts agenda, it's being done to save money rather than for the betterment of the individuals involved."

The same holds true, she feels, with regard to the budget announcement that Disability Living Allowance (DLA) will, from 2013, be subject to a medical assessment. But Ms Begg says this is also totally at odds with the philosophy behind DLA.

"The one benefit which we have in this country which actually operates on the social model of disability is DLA. And to turn it into something which you only get if you actually have a medical diagnosis detracts from the whole purpose of DLA."

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Government website spawns hate

Cathy Reay

A Government website set up to allow the public to suggest ways of cutting public spending has drawn torrents of disablist abuse.

Suggestions have been posted on the Spending Challenge website, which was set up last month by the Treasury to allow people to suggest ways to cut government spending.

They include proposals for the sterilisation of benefits claimants, disallowing family members to claim carers' allowance and stopping individuals with "drug and alcohol problems" from receiving Disability Living Allowance.

The Government has said that the idea behind the site is that the more popular the suggestion, determined by the number of user-generated votes and comments it has, the more seriously it will be regarded by the Treasury.

The fifth most popular suggestion is currently to "stop benefits for immigrants until they have paid [sic] into the system for five years".

Lisa Hamilton*, a disabled woman from Yorkshire, said she is very upset that these comments have been allowed on a



Government-owned website.

"I honestly believe the Government knew this might happen, so that when they bring in all their lovely cuts in a few months they can say that they are as nothing compared to what a proportion of the public wanted.

"I just can't believe that a Government website could allow this sort of thing. Isn't it illegal to incite racial and disablist hatred?"

Steve Donnison, disability and welfare rights activist and author of a benefits and work blog (benefitsandwork.co.uk), said: "I'm just shocked and revolted that it

is now possible to visit a website which has the HM Government logo at the top and a discussion about sterilising claimants on the rest of the page.

Mr Donnison added: "Just because the discussion gets removed a few days later does not make up for the fact that it was published by a Government website in the first place. What's so revolutionary about moderating posts before they are published?"

A Treasury spokeswoman said: "We want the public to offer their views and ideas, but we clearly don't welcome offensive and

inappropriate remarks. We have actually received thousands of positive and constructive responses on the Spending Challenge website, and there are strict guidelines in place to ensure any inappropriate comments are removed."

At the time of writing, none of the disablist or racist suggestions viewed by *Disability Now* that were posted on the website over a five-day period had been removed by administrators.

• **The Spending Challenge website can be viewed at spendingchallenge.hm-treasury.gov.uk/**
*Name changed to protect identity

newsupdate

Disabled children trapped in poverty

Sunil Peck

Nearly 75 per cent of disabled children are denied days out because their parents cannot afford to take them, a report has found.

Counting the Costs 2010, published by the charity Contact a Family (CAF), surveyed more than 1,100 parents of disabled children in the UK about their financial situation.

The report, a follow-up to a similar report from CAF in 2008, shows that the number of disabled children denied days out has risen almost 20 per cent since 2008.

Other statistics showed that 40 per cent of parents had applied for grants from charities, a rise of 15 per cent, and that the number of families unable to heat their homes had risen from 16 to 23 per cent.

Tracy Davis, unemployed mother of nine-year-old Brynley, rarely goes out and does not drink, smoke or buy new clothes, so she can afford the additional costs incurred by her son's disability such as heating the home, clothes without buttons and zips, a low-fat diet and breakages to household goods.

She said: "He has



CONTACT A FAMILY

Pinched: Dawn Elliker and daughter Katie can't leave home

repetitive compulsions, one of which is that he likes to be driven to the countryside on the same route. This is often the only way we can control his behaviour and costs us about £70 a week in petrol."

But she said that car journeys are unsafe because Brynley has been assessed as requiring a car seat which she cannot afford because it costs more than £400.

Jacqueline Leech is a

nurse by profession but does not work. She says she would be worse off financially if she worked because she would lose child tax credits and have to pay a specialist childminder because her 13-year-old son Christopher has behavioural issues.

"Christopher wants to do all sorts of things like going to military museums and castles, but we can't afford it. He gets angry and

frustrated and his behaviour gets worse."

She added: "Social services have worked out that I can get a carer for £10 an hour. But specialist carers cost £15 or £20 an hour. I get direct payments but that doesn't cover the additional costs of employing a carer."

Srabani Sen, Chief Executive of CAF, said: "Many families with disabled children are in financial dire straits. Everyone has been hit hard by the recession but families with disabled children were already having to cope with a harsh combination of extra living costs and the difficulty of holding down a job and caring. These financial pressures have been worsened by the economic slump and have left many at breaking point.

"Time and time again, research shows that families with disabled children have an above-average risk of living in poverty. Steps must be taken to address this imbalance from the Government, from businesses and employers, from local authorities and from the voluntary sector."

• Visit cafamily.org.uk to read the Counting the Costs 2010 report

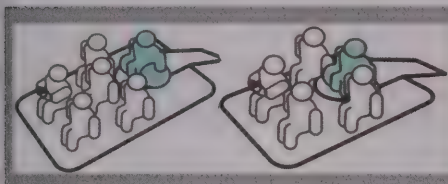
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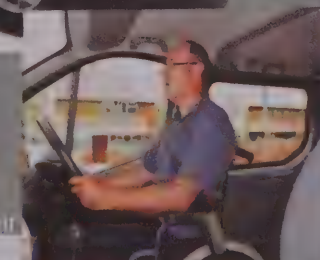
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- NORFOLK LODGE (Learning Disabilities) Horsham 01403 218876
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- RAPKYNs CARE HOME (Adult Care & Neurological Conditions) Horsham 01403 265096
- RAPKYNs CARE CENTRE (Physical & Learning Disabilities), Horsham 01403 276756
- WHITE LODGE (Learning Disabilities) Purley, Croydon 020 8763 2586
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email: corrine.wallace@sussexhealthcare.co.uk www.sussexhealthcare.co.uk



ruthpatrick

Turning up the heat on fuel poverty



With the economic outlook as bleak as coming winter weather, **Ruth Patrick** says it's imperative for the coalition Government to act early for disabled people in fuel poverty



Nick Clegg: forgotten policy pledge

The extent of fuel poverty in Britain today is a disgrace and must be addressed by this coalition Government.

A household is described as being fuel poor where they need to spend ten per cent or more of their income on fuel to adequately heat their home. In 2007, 2.8 million households were in fuel poverty, of which 2.3 million were categorised as vulnerable households as they included disabled people, children or the elderly:

For disabled people, the

situation is particularly serious, as many impairments are aggravated by cold, meaning that being unable to afford to heat one's home can have serious health consequences. For those disabled people who spend much of their time indoors, the costs of heating are correspondingly higher, further increasing their risks of living in fuel poverty. At the sharp end, fuel poverty can literally involve choices over whether to keep warm or eat adequately – a choice which no one living in 21st century Britain should be required to make.

All those aged over 60, regardless of income, receive a Winter Fuel Payment (WFP) of between £250 and £400 a year to assist them with the costs of heating their homes during the cold winter months. Unfortunately, these payments do not reach those most in need. Recent research by the think tank,

“Fuel poverty can literally involve choices over whether to keep warm or eat”

Policy Exchange, found that only 18 per cent of households in receipt of WFPs are fuel poor, whilst 49 per cent of all fuel poor households receive no WFPs. As a report by the House of Common's Energy and Climate Change Committee argued, WFPs in their current incarnation are an ineffective measure for helping the fuel poor.

This situation needs to be rectified and quickly. The coalition should extend WFPs to all those disabled people in receipt of high-level

Disability Living Allowance for mobility impairments. The Liberal Democrat's manifesto included the commitment to increase the age of eligibility for WFPs to 65, and use the money saved to provide WFPs of £200 for many disabled people. Now in Government as Deputy Prime Minister, Nick Clegg seems to have forgotten or abandoned this policy pledge, and the recent Budget contained no changes to the current system of WFPs.

Disabled people should remind Clegg of his earlier manifesto promise, and should join the voices of National Energy Action and the End Fuel Poverty Coalition in calling for measures to tackle fuel poverty. A good place to start would be a letter to your MP, asking them to act now on fuel poverty before even more people simply cannot afford to keep warm this winter.

• For details of current campaigns see: nea.org.uk and consumerfocus.org.uk/campaigns/end-fuel-poverty

→ Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
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politics



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Scots toast new pub access law

An amendment to licensing laws passed by the Scottish Parliament will potentially put some of the spontaneity back into a night out. **Sunil Peck** reports

Mark Cooper remembers feeling annoyed about the night in early 2009 when he had to leave the Edinburgh pub he was drinking in with mates so he could go to an accessible toilet. The pub they were in did have disabled access, but the nearest usable toilet for him was in another pub 200 yards along the road.

In fact, he was so angry that he started an internet campaign which attracted more than 700 supporters in its first week.

With the support of the

disability organisation Capability Scotland and the MSP George Foulkes, Mark's campaign gathered momentum and has culminated in the passing of an amendment to the Criminal Justice and Licensing Act in the Scottish Parliament which requires new pubs to show how accessible they are for disabled customers when they apply for a licence.

Speaking to *Disability Now* after the passing of the amendment, Mark, who now works as a parliamentary and policy officer at Capability

Scotland, said: "I am delighted that the hard work put in by me and my colleagues at Capability Scotland and George Foulkes has paid off."

The difficulties posed by the absence of access information were highlighted for Mark when he went out to celebrate the new law and he struggled to get his wheelchair through the door in yet another pub.

"That shows why this campaign is needed. We thought that because the pub had flat access we would be able to fit my

wheelchair through the door with no problem."

What about the pub with disabled access which Mark had to leave in 2009 in order to use a disabled toilet? Will the new legislation mean that Mark can now enjoy a few pints there?

"No. The point of the campaign is not to say that every pub should be accessible. It's about improving the access information available to disabled people so that they can make a choice about where they can go to."

The hope is that the

information will be made available for people to view online.

"The amendment says that people will have to provide information about the facilities in their premises as well as information on access and egress to and from the premises. So that is things like if the door to get into the pub is heavy as well as whether or not there are large print menus or disabled toilets inside."

Is he concerned about the pub trade's willingness to co-operate with the legislation?

"I am confident. I have had

"The pub they were in did have disabled access, but the nearest usable toilet for him was in another pub 200 yards along the road"

very positive feedback from the pub trade. I know the trade is struggling so if disabled people can have information about a particular pub, that pub could see an increase in sales."

Mark is still mulling over

how the campaign to promote greater access to pubs can be moved on. Perhaps it could be extended to cover premises which already have a licence. But he says that one possibility could be a mobile phone application for people to access the information when they are out which would eliminate the need to plan nights out in advance. He also talks about the possibility of broadening it to cover pubs in the rest of the UK.

"It's about independent living. Disabled people

should have the right to a barrier-free social life. Having to leave a pub just because you can't go to the toilet is social exclusion."

Mark says: "At the moment I tend to stick to the same places where I know that I'm not going to have a problem going to the toilet."

Meanwhile, south of the border throughout England and Wales, disabled drinkers who need accessible toilets will continue to have to stick to pubs they know or plan their nights out based on information gained from recces.

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mediawatch

By Cathy Reay

Keeping it real in Albert Square

Recently nominated for her 29th television award, there's no doubt that when Lacey Turner leaves Albert Square later this year she will be sorely missed. She may be the soap's golden girl, but has she authentically delivered her character's psychological meltdown?

Having, as Stacey Branning, endured some of the meatiest storylines in soapland, including drug abuse, adultery, murder and, currently, mental illness and motherhood, it is fair to say 22-year-old actress Lacey Turner is being stretched to her limits as she sets the groundwork for her typically explosive Walford exit.

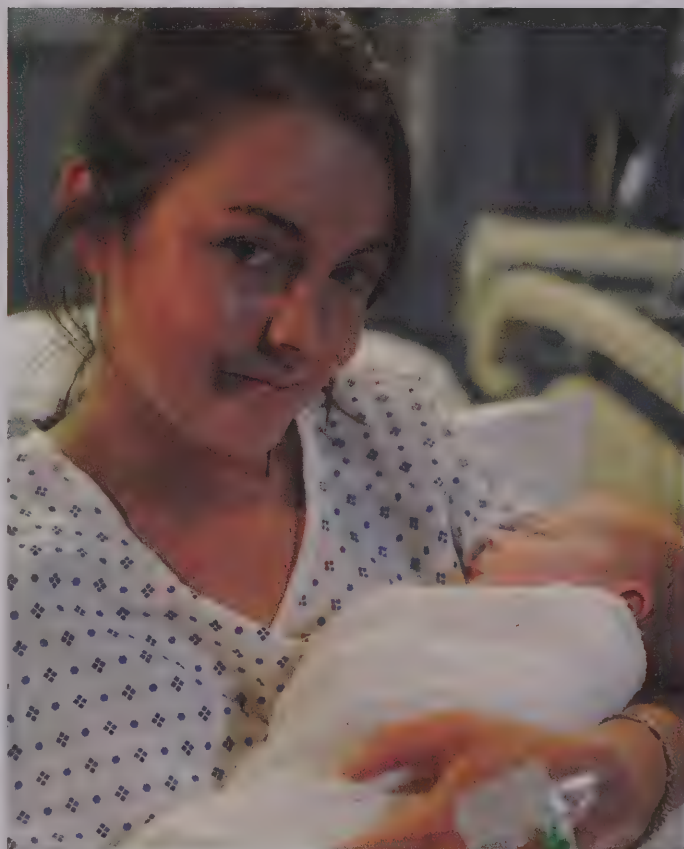
EastEnders researchers decided to develop Stacey's bipolar disorder storyline after the positive reception her bipolar onscreen mother Jean, played by Gillian Wright, received in 2006. Stacey, who was already known for her teenage tantrums, began having more frequent, extreme mood swings last year and was eventually sectioned by the resident Albert Square doctor under the Mental Health Act, after an outburst in which she

accused everyone she knew of trying to hurt her.

The BBC drafted specialists and mental health charities like Mind and MDF the Bipolar Organisation (MDF) very early on in scripting Stacey's condition. In fact, the amount of preparation undertaken was probably the most extensive of any mental health issue raised in soap operas to date.

Siobhan O'Neil, who has bipolar disorder and closely consulted with the BBC on the storyline, says she offered herself as a case study because she wanted "to make a difference".

"I had to dig really deep and be quite vulnerable for the researchers, because I wanted to give the character the most honest experience she could have. The researchers were very empathetic, I could say anything to them and there was no 'recoiling in horror'.



It was a very empowering experience," she says.

When Stacey became pregnant later in the year, the programme's researchers had a lot of work to do debating how her medication might affect her ability to breastfeed, how her moods might change and how she would generally cope with the situation.

Dr Ian Jones, a reader in perinatal psychiatry at Cardiff University, was on hand to advise. He claims that *EastEnders* researchers wanted to make the storyline as realistic as possible.

"When they gave us outlines and scripts we

would change little things like the type of bottles medication would come in and talk together about the symptoms people have when they are unwell," he says.

Siobhan said that during the pregnancy stage there was too much focus on medication being "the answer".

"In reality things that happen in life can make someone wobble quite severely, regardless of what meds they are taking. You have to make lifestyle changes so old behaviours don't trigger bad experiences."

Siobhan also says she

would have liked to have seen the characters that referred to Stacey as "mental" and "crazy" be questioned within the storyline for their use of such hurtful language. However, she praises Lacey for her interpretation of someone with the disorder.

"The actress is incredible for someone who hasn't had that experience. She has nailed it."

Naturally, because Lacey has no direct experience of bipolar disorder everyone was ready to question her acting ability. Why didn't

the soap bring in someone that has bipolar disorder off-screen to play out the storyline?

Dr Jones says: "Even I can see that if she had had direct experience she would of course have benefited from that information when playing her role. But I think she's a brilliant actress and there were no complaints with her work."

Despite slight misgivings over small parts of Stacey's

story, Siobhan agrees that she's incredibly glad that *EastEnders* embraced such a difficult issue. "I am really pleased they were brave

enough to do it. I know it made a difference to people, they felt they were being heard and listened to. I'm incredibly sad that Lacey is leaving the show."

Neil Tinning, patron of the MDF and one of the BBC's advisers,

says: "The only way to overcome stigma is by education. While *EastEnders* is only a soap and not reality TV it is often treated as such but [thankfully] has had a positive influence on its audience so far. At the end of the day I'd rather be on the inside advising than an outsider throwing stones."

A website has been set up by Professor Nick Craddock and Dr Ian Jones with more information on bipolar disorder and the issues raised by Lacey and Gillian in *EastEnders*. Visit bipinfo.org for more information.



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Right to Pride denied

After years of participating in London's annual celebration of gay culture, **Ju Gosling** feels less proud of attitudes to disabled people at this year's event



I “came out” in June 1997, after the end of a relationship that had lasted longer than it might have done because my partner was also my carer. Shortly afterwards I went to London Pride, where I was relieved to feel welcome and part of the Lesbian, Gay, Bisexual and Trans (LGBT) community. I was proud to be gay.

I later discovered that Regard, the national LGBT disabled people's organisation, had been working with Pride since the early

1990s to make the march a blueprint for accessibility.

There was Blue Badge parking at the end of the march route and a shuttle bus that collected disabled marchers from there and the main stations and delivered us to the start.

There was a “safe space” at the front of the march, with manual wheelchairs and pushers for those who couldn't walk the whole route. There were also access stewards trained by Regard, sign language interpreters, and other

features that made Pride truly inclusive.

After that, Pride became – as it is for so many people – the place where I not only met old friends and made new ones but demonstrated publicly my pride in being gay.

Of course I joined Regard, and in due course became a co-chair.

In the noughties, though, everything changed. Suddenly Pride had new organisers who didn't want to take our calls. The access sub-committee was

disbanded and some of the most critical access arrangements were cancelled, including the parking and the provision of wheelchairs.

By 2007, when London hosted EuroPride, so few Regard members could access the event that we had to pull out altogether.

In 2008 and 2009 we fought back, supported by the late great David Morris, then disability adviser to the Mayor of London.

But despite us repeatedly contacting Pride's funders and sponsors – the Greater London Authority, the TUC, Unison – and Westminster Council, no one seemed to take us seriously. How can people who are asexual and genderless be LGB or Trans?

Unsurprisingly, the promises forced out of the Pride organisers to reinstate the access arrangements in full proved to be false. In 2010, access was still so poor that Regard had to pull out again. Instead of being at the event, I spent the afternoon working in uniform for Graeae, the disabled people's theatre company, who refused me permission to wear a rainbow Pride scarf.

Like many other queer crips, on 3 July I simply felt isolated, excluded and miserable. It's hard to feel proud of being part of a community that doesn't want you as a member.

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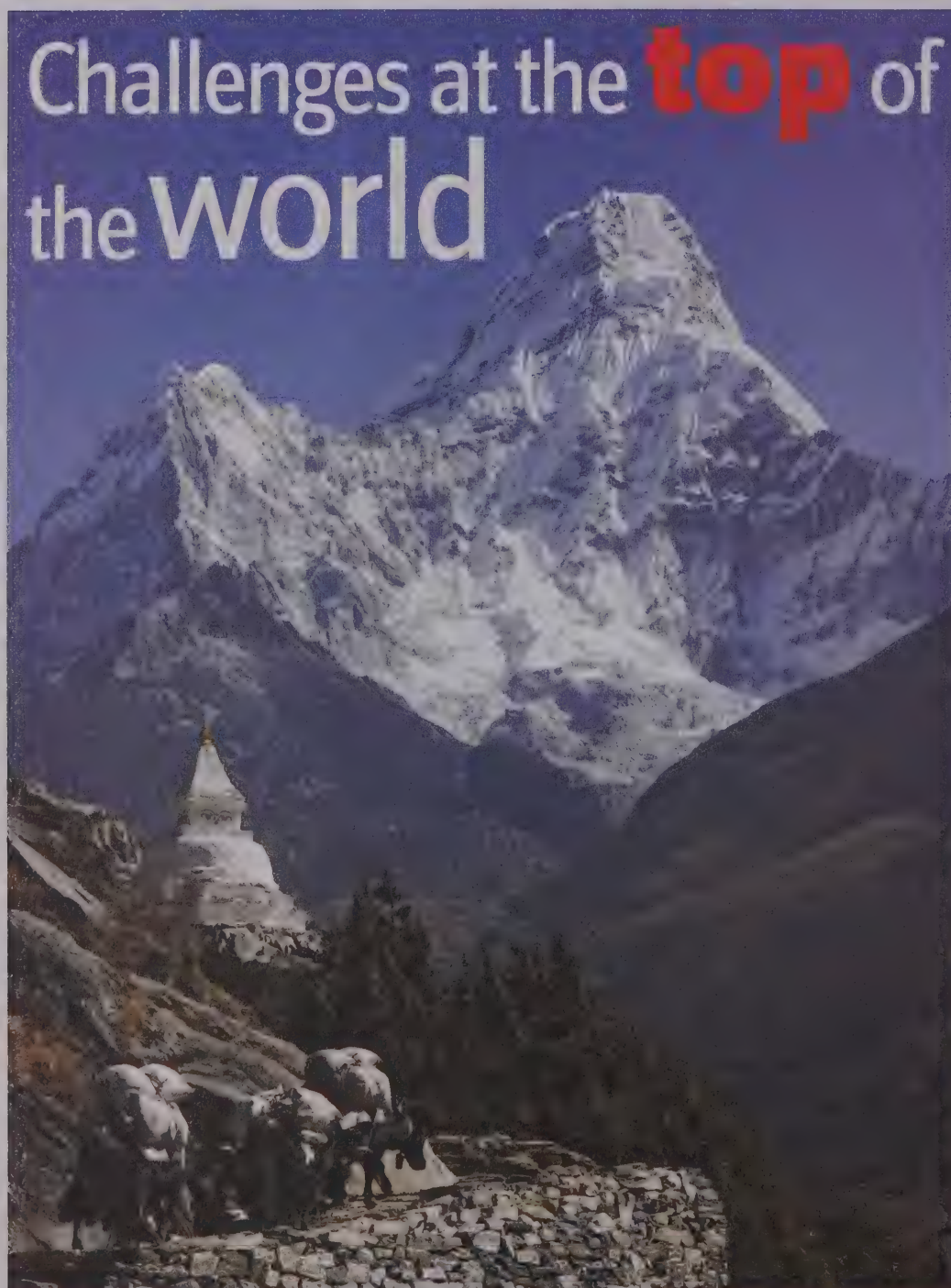
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worldview



The two years since *Disability Now* first featured Nepal in our World View section has been an exciting and challenging time for disabled people in the world's newest republic. Nepalese disability activist **Maheshwar Ghimire** (pictured right) brings us up to date on progress made and barriers still to be faced

Nepal ratified the UN Convention on the Rights of People with Disabilities in February 2010. This was a huge success. For us the door is open now but it will mean a lot of monitoring and we need to remake lots of domestic laws.

Our disabled people's organisation mostly deals with social issues that reflect the attitudes of society. We campaign on law enforcement by taking public interest litigations on behalf of disabled people. It's like a form of legal aid.

For instance, buried in the legislation on access to education, we discovered that no disabled people should have to pay fees for education. No one knew about this: it was kept in the cupboard. We took a case to court and after two and a half years the Supreme Court decided disabled people are entitled to free education.

We also won the case against detaining people with mental health issues in jail. These people had committed no crime. We won this in 2008. Again it took two and a half years.

If a Nepalese woman becomes disabled after getting married her husband can then take a second wife. In one case the first wife was forced to leave her home and live in a hostel because

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of domestic violence. We took the case and the court awarded her property rights she was entitled to.

Disabled people can often be denied their property rights. If they inherit land or a house their family can say: "You don't need it all. After all you aren't married and we'll take care of you." Two months ago we won a case. A deaf woman who was unmarried was being denied her property rights by her brothers but in court the verdict went her way.

Nepal is one of the few countries in Asia to abolish the death penalty and has ruled in favour of same-sex marriage. When a draft paper on minority groups excluded lesbian, gay, bisexual and trans (LGBT) people and disabled people, we joined together to demonstrate.

There is still no access to public spaces. The Government has introduced a building code but all we can do if we find a new building is inaccessible is report it. The Government is trying to make their offices accessible but private companies are only interested in profit.

Access to public transport is also very poor as it's run by the private sector.

Our geography is very challenging. We're on the top of the world. Some districts can only be reached by seven or eight days of



Buried in the legislation on access to education, we discovered that no disabled people should have to pay fees for education. No one knew about this: it was kept in the cupboard ☹

walking. Mountain villages have very poor facilities so often disabled people have to leave their villages and come to urban areas. There is a displacement of disabled people.

Most secondary school students walk for an hour to get to school. This means many disabled students are excluded.

Another big challenge is the caste system. If a disabled person is of a low caste they face double discrimination.

There's no reliable data on the number of disabled people in Nepal as families

are not willing to admit they have a disabled family member: it's a social prestige issue. In preparation for the 2011 census we're broadcasting spots on community radio stations on the importance of counting disabled people in the census. The Government has just started a very nominal monthly allowance for disabled people so hopefully that will encourage people to identify themselves as disabled in the census. We're also persuading the census enumerators not to ignore disabled people in the count.

We have limited capacity so we're trying to hand over knowledge to smaller organisations. Our ultimate aim is to develop the capacity of local disabled people's organisations.

The Disabled Human Rights Centre is in a crucial position as Nepal's new constitution is being made. We're trying to get the voices of disabled people to the government body by

using theatre as a tool. Using street theatre to interact with large groups of people from different castes speaking different languages saves on the cost of communicating with lots of small groups.

Disabled people from all over Nepal come to Katmandu to do two weeks of theatre training and then they go back to their communities. We use the ideas of Augusto Boal: a play is stopped and the audience is asked what should happen next. In this way we're collecting ideas on legal issues and how to tackle discrimination. It's almost like legislative theatre.

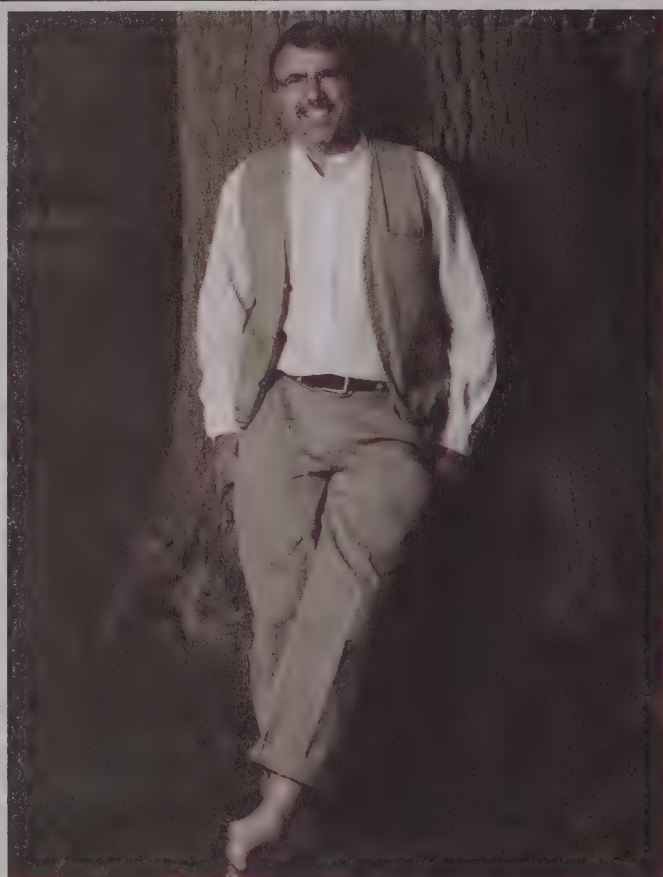
We have 9,000 written suggestions of what should go in the constitution, law, policies and services. When the first draft of the constitution comes out, we'll go back and ask disabled people what they think. It might be fantastic but enforcement might be weak.

Currently there is political deadlock until issues are resolved between the state and the last of the Maoist combatants who have opposed the Government. Fingers crossed, we should have the first draft of the constitution next year.

We face many challenges but we have great opportunities. We're at the very very beginning.

• Maheshwar Ghimire was talking to Kelly Mullan

one2watch



Taking it to the people

Norfolk-based social entrepreneur and writer Robert Ashton is *The People* newspaper's new voice on national mental health issues. And Stuff Stigma, a think tank founded by the campaigner to challenge prejudice and promote well-being in Norfolk, has reached the semi-finals of the National Lottery Awards 2010. Now the man responsible for introducing the concept of the "human library" to

Norfolk lets *Disability Now* check him out.

What's the best thing about being disabled?

I don't really see depression as a disability, it can actually be more of a gift.

What funny things get said about your impairment?

The greatest compliment I was ever paid was when someone said I was "both brilliant and annoying in equal amounts". I guess

that's the joy of being both bright and slightly bonkers.

If you were Prime Minister, what would you do to improve things for disabled people?

If I were Prime Minister I'd encourage those in the public sector to throw out the rule book and listen to their intuition. I'd have people take responsibility, take risks and do what feels right – not blindly follow inflexible rules.

What invention could make your life better?

I'd like to see conversation reinvented; people making time to talk to each other, to understand each other's point of view. We all need to value people more.

What do you like most about blogging?

It's anarchic, free and unrestrained. We all have a voice and the opportunity to debate.

What do you like least about blogging?

As with any writing, less means more. Wordy blogs

take ages to read. I'd limit all blogs to 200 words.

Who is your favourite disabled person?

I'd hate to differentiate on the basis of disability, but I do have a great admiration for Salvador Dali. He said: "The only difference between me and a madman is that I am not mad." That pretty much summarises my outlook on life.

Can you sum yourself up in ten words or less?

Unconventional, campaigner, sensitive, author, blogger and a budding dissident.

What makes you angry?

Prejudice makes me very angry. People need to look and listen before lobbying rocks.

Do you have any hidden talents?

It's not for me to say I have hidden talents. I am very happy being me. Talents are things others value and so depend upon how I can help them.

→ Who do you think is One to Watch?

Send us your nominations for likely lads and lasses who could answer our 10 questions. They can be rising stars in any field of entertainment, business, the media or beyond

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Result! You've chosen your
DISABLED LEGEND

Back in our April issue we asked you to vote for *Disability Now's* Disabled Legend in our readers' poll. The 50 candidates, all disabled, were drawn from people from past and present. They included artists, entertainers, writers, musicians, scientists, politicians, sports people, campaigners and activists. They were nominated by *Disability Now* staff and freelance contributors, all of us disabled. Some of the nominators championed their favourite nominee...then it was over to you! And now we publish the result of your vote.

WINNER: Baroness Jane Campbell

Member of the House of Lords, co-chair All Party Parliamentary Group on Disability and former commissioner at the Equality and Human Rights Commission.

No one better illustrates that working behind the scenes doesn't mean you're not appreciated or don't produce results.

With a long and incredibly impressive history of parliamentary campaigning, Baroness Jane Campbell of Surbiton DBE continues to be an inspiration to the disability sector, including some who were shortlisted in our Disabled Legends survey.

Baroness Campbell tells *Disability Now* why she values our poll. "I don't think any of our different contributions to the world of disability can be graded. I just think what I'm doing currently probably resonates with a lot of disabled people and our allies. It's a very good way of consulting people I don't know, so thank you *Disability Now* readers! This

gives me energy and drive."

Having recently been appointed co-chair of the All Party Parliamentary

"The prize for me is emancipation. I can't do anything without other disabled people beside me telling me where we should be going next"

Disability Group (APPDG) alongside Anne McGuire MP, Baroness Campbell is busy working on the implementation of the UN Disability Convention, an accessible democracy and disabled people's priorities for the new parliament.

Within parliament Baroness Campbell is working on expanding the Right to Control to cover health services and any other public support services.

"I'm fighting anyone or any group who attempts to weaken the criminal justice system with regard to assisted suicide and a right to portability of

personal support packages."

From 2006-2009 she worked as a commissioner at the Equality and Human Rights Commission and from its inception in 2000 to its demise in 2006 a commissioner at the Disability Rights Commission. Additionally in the 1990s, Baroness Campbell authored several disability rights-based publications.

Commenting on her relentless energy and drive, she says she has "an incurable curiosity and desire to make things better for everyone, including myself. I think I am hyperactive, so that gives me the drive one probably needs to constantly remove barriers in pursuit of the prize. The prize for me is emancipation."

"I can't do anything without other disabled people beside me telling me where we should be going next."

There really is 'nothing about us, without all of us, or at least a lot of us'. I'm definitely not dead yet so watch out, there's more to come!"



Disability Now Editor Ian Macrae says: "Thanks to all those readers who took the time and trouble to vote in our poll. Each of our top three shows that the cause of disabled people's rights and equality can be advanced in different ways. Each one of them has credibility in their own field. Baroness Campbell, having moved from activism into the establishment has taken the battle with her. Alan/Johnny Crescendo has used his talents as a performer and zealot in the fight for more choices and rights. Tanni Grey-Thompson has used her status as a world-class athlete and public figure to challenge perceptions. They've all done their bit to raise the profile of our community."



IN SECOND PLACE: ALAN HOLDSWORTH

AKA JOHNNY CRESCENDO (Performer and disability activist)



Alan Holdsworth, or Johnny Crescendo as he is known to fans, is a singer with a difference: his rhymes aren't the atypical love story, they're about disability rights. British but now living in north America, he tells *Disability Now* he is "pleasantly surprised" to come second in our inaugural Disabled Legends poll.

"I don't know why people voted for me but I am glad that activists, that is people who campaigned to improve the lives of disabled people, finished ahead of "role models" or

“I am glad that activists, that is people who campaigned to improve the lives of disabled people, finished ahead of “role models” or famous people”

famous people:

"Perhaps people voted for me because, as that guy who was arrested many times on Direct Action Network actions, I have a certain Robin Hood charisma?" he jokes.

Alan said he is currently planning a tour of the UK and Northern Ireland in early 2011. "It's called the Songs of Freedom tour. I've reached a time in my life when I believe it's time to pass on what I've learned and to share the successes and failures with audiences in the hope that we can rekindle the activism of the '60s and ensure that no group of disabled people is left behind."

• For tour dates or more information, visit Alan on facebook facebook.com/JohnnyCrescendo

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IN THIRD PLACE: TANNI GREY-THOMPSON

(Sportswoman and campaigner)

She may have retired three years ago but Tanni Grey-Thompson's working life is far from over. One of the most successful disabled sportswomen in history tells *Disability Now* how honoured she is to be placed third in our poll.

"It's really interesting that even after three years I guess I am still in the public consciousness, to have disabled people themselves vote for people who aren't known because they have some celebrity status, who are activists, feels

more 'real'," she says.

"I recently became a life peer in the House of Lords so at the moment I am learning a huge amount from Jane [Baroness Campbell]. It's great to finally be putting something back in now, I want to go in and make a difference on the issues that matter to me as a disabled person, mother and human being. There are really interesting times ahead in terms of personal care, benefits and education and I think there may be a bit of a fight - but I'm ready!"



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(aka Johnny Crescendo)



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Tanni Grey-Thompson



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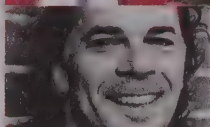
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6th 4.4%

Lord Jack Ashley



7th 3.4%

Ian Dury



8th 2.6%

Tom Shakespeare



9th 1.6%

Helen Keller



10th 1.5%

Stevie Wonder

Shortlisted (in alphabetical order): Rick Allen, Muhammad Ali, Ludwig van Beethoven, Collin Barnes, Jean-Dominique Bauby, David Blunkett, Louis Braille, Patricia Chambers, Sir Winston Churchill, Ian Curtis, Chris Davies, Albert Einstein, Michael Flanders, Michael J Fox, Stephen Fry, Frank Gardner, Evelyn Glennie, Goya, Joseph Grimaldi, Adam Hills, John Hockenberry, Rachel Hurst, Dr Samuel Johnson, Frida Kahlo, Henri de Toulouse-Lautrec, T E Lawrence, Sir Bert Massie, Curtis Mayfield, Spike Milligan, Claude Monet, Christopher (Christy) Nolan, Mike Oliver, Oscar Pistorius, Sylvia Plath, Franklin D Roosevelt, Nabil Shaban, Vincent van Gogh, Peter White, Brian Wilson, Sir John Wilson

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Since the Chancellor, George Osborne, announced in his emergency Budget speech that the Government intends to save £1.4bn by changes to Disability Living Allowance, (DLA), *Disability Now* has been inundated with calls, letters, emails, tweets and website comments from disabled people right across the country.

They're deeply concerned about the impact the changes could bring.

So, what exactly has the Government said? The reality is, not a lot. The Budget document stated that from 2013-14, all new and existing claimants of Disability Living Allowance would be subject to what it calls an "objective medical assessment". As yet there is precious little information available as to what form these assessments will take, or who will be responsible for conducting them.

In its financial breakdown, the Budget document claims that the cost of DLA has quadrupled in real terms since its introduction, and that the proposed assessments would save the Government £1.4bn by 2015.

The move has left many disabled people confused and angry.

Anne Novis, disability campaigner and a trustee of the United Kingdom Disabled People's Council (UKDPC) says she is "appalled" by the move.

"How anyone cannot see this Budget is targeting the most needy in society is beyond me," she said.

"The thought of a nurse or locum GP doing a medical on me with no knowledge of spine injury and the resulting consequences re pain, debility and side effects of medication makes me feel sick to my stomach.

"I dread trying to manage my finances when I already struggle and this atmosphere of being under siege



Osborne: opening Pandora's box

"Afraid." "Anxious." "Frightened." "Scared." These are just some of the words used by readers of *Disability Now* to describe their feelings over the proposed reform of Disability Living Allowance. **Paul Carter** reports

by this Government is causing huge anxiety. I have already made enquiries about food parcels as I just don't know how I will manage if any of my benefits are reduced in any way.

"It is also inciting hatred towards disabled people; if our ministers can revile us then others feel justified in also doing so. I have been called a fraud on the streets, given nasty stares and told I am a burden to the state. I have been told I should have been killed at birth and, as I was not, should be killed now.

"If this Government can get away with encouraging such hostility towards us where can we turn for protection and safety?"

The Government's slowness to provide further details has led many people to question its ethical position. Several readers have told *Disability Now* that they are already so worried about the plans that their wellbeing is beginning to suffer.

"The constant stress of not knowing what is happening is having a negative affect on my health," says one reader. "I did have an indefinite award, now it appears I will be under scrutiny."

Another says: "It seems we are all going to have to again go through the stress of another medical just so this new Government can again prey on the most vulnerable of society.

"How can they now decide to change this? I would challenge Mr. Osborne to live in my shoes for a week and then make his decision on this totally unacceptable move. We must all stick together and let them hear our voice."

Along with the fear and apprehensions over the proposed assessments, many people who have spoken to *Disability Now* are angry about what they perceive to be a demonising of DLA claimants as "scroungers".



Above: Anne Wollenberg's facebook group; below: Anne Novis



Disabled journalist and DLA recipient Anne Wollenberg set up the Facebook group "Petition to stop George Osborne's attack on DLA", (facebook.com/group.php?gid=131151876919497&ref=ts) which has already attracted over 800 members.

"I'm doing all of this because I'm worried, really worried, about the false information the Government is disseminating about DLA," she said in an email.

"They're implying it's a benefit for people out of work e.g. as per the State of the Nation report which said:

'There is a high degree of persistence among claimants of many low-income and out-of-work benefits... For example... around 2.2 million people, including 1.1 million people of working age, have been claiming DLA for over five years'. That's not what DLA is.

"They're implying that if someone has a job they don't need DLA. The minimum wage doesn't go up, and the price of food doesn't go down, because you have a disability and life costs more.

"I dread trying to manage my finances when I already struggle and this atmosphere of being under siege by this Government is causing huge anxiety"

"They're implying that it's rife with scroungers when DLA has the lowest fraud rate of any benefit.

"All of this is making people think DLA claimants are scroungers."

Writing on his blog (mikscarlet.blogspot.com/2010/07/were-for-chop-or-my-life-as-scapegoat_05.html) journalist and tv presenter Mik Scarlet said he wants to challenge "the hypocrisy of the current scapegoating of disabled people."

He said: "Now we are rushing towards a new dawn for disabled people, where we are to all be reassessed for all our benefits, whatever the cost of that procedure is to the tax payer, and some will be expected to battle to get a job in a hostile work environment and thus end up on a different and lower form of benefit, and the rest will be scarred by the fear that this scapegoating of disabled people causes.

He continued: "For all of us, it spells the end of the feelings of pity and sadness that we once caused in the



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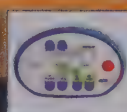
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general public, and that we hated, to have them replaced by much worse feelings, deep resentment and mistrust. Personally I think this Government should hang their heads in shame."

“They're implying that it's rife with scroungers when DLA has the lowest fraud rate of any benefit. All of this is making people think DLA claimants are scroungers”

Elle Wellesley, who runs website Stiletto Wheels (stilettoheels.co.uk) agrees.

"I am very unhappy at the PR campaign by this Government to vilify the entire disabled community by labelling us as 'fraudsters' or 'undeserving' AND implying that we are able to work 'on the same basis' as those without disabilities – completely ignoring the overt discrimination, the physical barriers to our participation in society and the pain and difficulty many of us have to deal with every single day – all significant obstacles we must overcome and which are unlikely to ever be eliminated completely. It is nefarious to suggest there is equal opportunity/ability in the workplace for those with disabilities when surveys AND real life illustrate so clearly that this is not the case."

At the time of going to press, *Disability Now* was still awaiting responses to questions about the plans from the Department for Work and Pensions.

We will continue to press the Government for greater detail and transparency over the form and reach of their proposals. Lives depend on it. ■

One reader, who doesn't wish to be named, shares their personal account of the fear and uncertainty caused by the reform announcements:

I am particularly frightened by the proposed changes to DLA.

My circumstances are that I am an above knee amputee, who cannot use a prosthetic leg due to arthritis and heart disease and effects of diabetes polyneuropathy and other associated physical problems.

I cannot use a manual wheelchair because of health conditions, or even turn a tap because of arthritis, and can only get around with the help of a powered wheelchair.

In addition to physical problems I have a history of mental health issues and have recently been referred to counselling and diagnostic for an autistic spectrum disorder, Aspergers.

Since leaving school at 16 I have worked, and even after having my right leg amputated continued to work, even through my hospital stay.

I am unable to care for myself and get help with cooking meals, house cleaning and getting out of the house.

My employer is very supportive and arranges for me to get to and from work, and supports me if I am unable to attend due to ill health and problems.

Looking at what this Government and the previous one says I am the

"ideal" – even though I have problems I work, volunteer to help elsewhere where I can, and despite being classified as a vulnerable and disabled person contribute to society.

The new proposed measures to address DLA will have a devastating impact on someone like me; I have no social life without support and cannot live totally independently without support. If these proposals are carried out to the degree I think they will be, it will mean although I am willing to work I will be unable to live. If the new criteria for disabled people claiming DLA is introduced and the consequences implemented and the result is that I lose my entitlement for my current rate of middle rate care and higher rate mobility, I will also lose entitlement to working tax credits and housing benefit, and more importantly help with care.

My life will become impossible and through neglect and not being able to look after myself I will end up in a place of no return. About 18 months ago I lost eight stone in four months because I was unable to shop and look after myself.

Mine is no sob story – people have to cope with far worse – but as someone in his 50s living alone this Government, and I have to say the previous one, do not care. A society is only as strong as its weakest members.

yourviews

Off the buses

I read with interest the article about accessible buses (*"On the buses"*, *Disability Now*, July 2010). However, it's no good having accessible buses if they're not matched by accessible bus stops. Bus stops, especially in rural areas, are often sited in the middle of grass verges, which wheelchairs and those with limited mobility cannot get to easily. They may also be located next to dropped kerbs, which is also difficult.

As far as I know, there's no government requirement to upgrade such bus stops. In Gloucestershire, the county council, to its credit, is currently monitoring bus stops throughout the county, so it can prioritise which stops need upgrading and which are most used. I'd urge people to contact their own local authority to find out what they're doing and, if necessary, lobby their local MP to take this up with the relevant government department.

That said, it has to be realised that little-used stops will be the last to be upgraded and given the current financial climate, any improvement will probably be a long wait.

Ray Sherman,
Cam, Dursley, Gloucs

Does reduced mobility make using public transport hard for you? Do you struggle to board tubes, buses or trains or are you forced to make complicated journeys to get to a "step-free" station? If so, the London Assembly Transport Committee would like to hear from you.

We're examining the experience of people with reduced mobility on the capital's transport network. This includes people in wheelchairs, older people, and people with children.

We're looking at how accessible the network is, from journey planning through to using each form of transport and inter-changing between them.

We now have a website where you can share your views. The deadline for comments is 30 September.

For more information see: london.gov.uk/assembly/transport-access.

To contact us, email Ross Jardine at ross.jardine@london.gov.uk, or phone 020 7983 4206, or write to him at the London Assembly Transport Committee, Freepost LON15799, City Hall, The Queen's Walk, London, SE1 2BR.

Val Shawcross AM, Chair,
London Assembly
Transport Committee



Chairman: Southwark Disablement Association's Pat Horan

On a recent trip to Northallerton, my nearest town, I decided to go by bus. I use a mobility scooter and was rather put out when the bus driver said "you can't come on here with that."

After a bit of "discussion", he finally backed down, but not before a passenger objected to the scooter's having a petrol engine. In fact it has an electric battery!

It's worth mentioning that we live on the edge of a rural area, with five buses each day in each direction.

After this experience, I'm reticent about using the bus again. I rang Hambleton District Council and was told that it's up to the driver's discretion. In

other words, if one driver agrees to take me to Northallerton, I could end up stranded if another driver refuses to bring me back.

Michael Peake,
Hutton Rudby, Yorkshire

After reading the article about buses, I made a few phone calls and found that wheelchair-users don't use buses here in Sutherland, Britain's largest county.

One bus company said it would rent me a bus with wheelchair access, (the whole bus just for me!); the other asked me to phone them when I wanted to go shopping. If they had a bus

in the area, and going in the right direction, they'd tell me. Getting back home was another matter, however: it could be days!

So here it's a simple case of: No Car – No Shopping.

It would also appear, I gather from some disabled people, that the buses are designed with high steps that are likely to defeat anyone on crutches, or even using walking sticks. One chap had to be lifted up, step by step, by other passengers to get on a bus.

R. Naylor,
Sutherland Access Panel
Eurogrind@aol.com
sutherlandaccesspanel.org.uk

I can't drive at the moment, so I got a bus pass and called the bus company to ask about accessible buses. I was told what bus to get but advised to phone on the day I wanted to travel.

I did so but when I went to the bus stop, the first bus to come wasn't easy access, so I waited for the next one. Same again. I had to let four buses go by before an easy-access one came, but when the driver tried to pull open the ramp, it was screwed down. The driver was sorry but I was very upset. It's time public transport was made more accessible.

Kathleen Mitchinson,
by email

Under the RADAR

Comments on RADAR's work on supported employment ("Fear of coalition cuts heads TUC agenda", *Disability Now*, 15 June 2010) do not give a full picture of the issues.

RADAR supports the comments made at the TUC disability conference that disabled workers could be particularly at risk from public sector cuts. We need to be vigilant in tracking whether this is happening and RADAR will speak out if disabled people are found to be suffering job loss disproportionately.

We also need to work together to ensure strong implementation of the Equality Act. RADAR worked closely with Baroness Jane Campbell and others to achieve significant amendments to the legislation as it went through Parliament (more significant on disability than in other areas), including the prohibition of pre-employment health questions. We will be working with partners to do everything we can to ensure effective implementation.

As the Government designs its new employment programme and looks at the future of programmes like Work Choice and Access to Work, RADAR believes it's crucial that it's informed by what disabled people want

from employment and the support that goes with it.

RADAR is therefore carrying out a study of what disabled people want and what helps to deliver it. This is not a feasibility study (as stated in your article) but a study of what we know from consultations, research and interviews with disabled people. For example: disabled people consistently say they want decent pay – a living wage or at least the minimum wage – yet some are paid below that. Our

work looks at ways to turn things round on that issue, and on others.

The result of this study will be a discussion document to start a debate and inform policy development, not recommendations set in stone. We have talked with trade unionists, disability leaders, academics, service providers, disabled people and more. We encourage everyone to join the debate as it develops.

Liz Sayce OBE, Chief Executive, RADAR

Where's the pride?

The pronouncements on benefits by Iain Duncan Smith, the new Secretary of State for Work and Pensions, have brought up all the usual misconceptions about disability.

I've been listening to LBC and reading the *Daily Mail* and people just don't understand the barriers there are to work. People say to me: "You don't look disabled." Or: "Other people are disabled and they work."

They don't understand the struggle to get access to hairdressers, shops and transport, never mind

access to the support needed to work. We need a stronger, more confident voice to educate people about disability.

Disability Now is great but it isn't mainstream. I read it in a public library but it's hard to get it anywhere else. *Disability Now* needs to be mainstream and we need a TV programme like *See Hear*. Look at how the gay community and people with mental health conditions have successfully lobbied against prejudice. We need a disability pride movement.

Nicola Prev, by phone

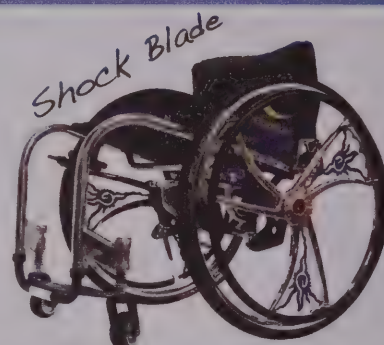
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andyrickell



Welfare reform: the real deal

Rather than government proposing welfare reform that is really a euphemism for saying benefits cuts, **Andy Rickell** asks why not some real welfare reform, that would benefit us all

I have an idea for true welfare reform based on some principles. Firstly, the new system must be simple for the disabled person to understand and to participate in, supported if needed. Secondly, the state's right to challenge a welfare claim must be balanced by the disabled person's right to have expert advice. Thirdly, the system must be fair between disabled people, and fair between the disabled person and the rest of society. Fourthly, the system must be transparent, with the right to a fair appeals process. Fifthly, it must be based on the disabled person's right to independent living, to choice and control, and to individualised solutions. Sixthly, it must be holistic so that it deals with the person as a whole individual, and joined-up so that state support is used well. Seventhly, it must minimise the administrative costs, to maximise the benefit getting to the disabled person for a given cost

to the taxpayer.

Here's how it would work. We have a single annual supported self-assessment process for all state support to the individual – current cash benefits (eg ESA, DLA, IS etc) and benefits in kind

It would result in an holistic identification of barriers faced leading to an holistic individualised solution

(eg community care, access to work, specialist employment support etc) which could then be offered as a direct payment or individual budget. The disabled person has access to an adviser trained in understanding independent living support and state funded, though probably employed by a voluntary organisation, to complete their assessment. The assessment process could be online like tax self-assessment, and like tax, the assessment form can

be split up so you only need to complete the relevant bits.

The assessment is reviewed by a civil servant trained in understanding disabled people's needs, probably employed by DWP, who would be the single funding conduit. The civil servant could challenge and ask for further proof of entitlement. Their final decision could be appealed, through a Disability Appeals Tribunal, which includes a disabled member, and where the disabled person would be properly represented.

The resulting entitlement would then be in the hands of the disabled person, with support to use it if they needed.

There would be no need for multiple assessments, no need for multiple sets of politicians/civil servants/social workers to act as assessors or gatekeepers (and hence

billions of savings), no problems about postcode lotteries, no problems about looking at the disabled person's needs/rights in isolation, no problems about decisions being made on inaccurate/incomplete information, no problems about the balance of power between claimant and the state.

It would result in an holistic identification of barriers faced leading to an holistic individualised solution, and hence most likely to result in the best quality of life outcomes for a given cost, including maximising the individual's capacity to take up a career, to manage their own life or otherwise contribute productively.

And there are lots of other ways to save public money and still end up with a better deal for disabled people.

→ Have your say

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Access and Environment AGNES FLETCHER

Disability trainer and consultant

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KATE SHEEHAN

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Motoring and Transport HELEN DOLPHIN

Works with Mobilise and specialises in car matters

Help! I can't tolerate electricity

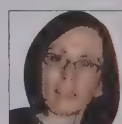
Q I'm very severely disabled (bed-bound) with a chronic illness and totally reliant on a power chair to get to the bathroom and remain independent.

Because of my illness I've also developed electrical hypersensitivity (EHS: please see the website es-uk.info for more details) and my power chair now makes me even more ill. I'm too weak to self propel a manual chair. I need desperately either a wheelchair that can be easily manoeuvred with very little strength by some kind of lever device or a wheelchair powered by something other than electricity. Any ideas? Or could you or someone you

know design or adapt a manual chair so it fulfils my needs?

Sarah Wheeler, stage manager

Agnes Fletcher says:



Sufferers from EHS can find it hard to get a sympathetic hearing in the UK. Doctors here often see it as a psychological condition. In Sweden, by contrast, EHS is officially recognised as a functional impairment.

For those who know little about it, imagine not being able to use a mobile phone, computer, microwave or any other modern essentials, or to tolerate therapies and medical equipment in which electricity is integral. There's

a useful summary of how this impairment is currently viewed in Sweden on the es-uk.info website. That website also lists products and services but nothing along the lines you suggest.

I suggest you get a proper assessment of your needs from social services, and specifically from an occupational therapist. The point is that, whether or not a non-electrical chair exists or could be created, you might gain from personal assistance with getting up, washing, using the bathroom and preparing food. Also, a review could assess whether you are claiming all the benefits to which you are entitled. (Depending on your circumstances, it might cost you, though.)

Electrosensitivity UK - es-uk.info - is a website for people affected by electrical appliances

I'm afraid of the outside world

Q I am 26 years old and have a learning disability. I feel scared going out on my own. Does anyone have any advice?

Name supplied, by email



Simon Parritt writes: Being scared in the outside world

is understandable when you read about all the bad things that can happen. Disabled and vulnerable people can be picked on and bullied. Fortunately, however, although such incidents are serious, they are very unusual. Most people never experience such terrible things.

I wonder if, like many disabled younger people, you're not used to going out on your own. Perhaps, when you go to the shops, meet friends or travel on the buses, you're usually accompanied by a carer or close relative. If so, you'll need time to learn how to feel safe and independent.

Try to find someone to help you with those first steps. Plan a place you'd like to go. A friend you trust can go with you part of the way and then you can go the rest of the way by yourself while your

friend waits close by. Also, use a mobile phone, so that if you feel anxious you can call your friend and talk to them: that will reassure you.

Go on short trips first. That way, before your anxiety gets too much, you can go back home so you never get too anxious. Try going down the road and back. When you feel OK, extend it: make a trip to a shop nearby and then come back. Reward yourself and buy yourself a small treat.

Have you become isolated and socially excluded? If so, you could join a club like Stars in the Sky, which is a friendship and dating service for people with learning difficulties. Find others whom you can meet and share your feelings and fears with (see starsinthesky.co.uk).

Finally, if you're really fearful and need more professional help, speak to your GP, who can refer you to a psychologist who specialises in these kinds of problems.

Many people find themselves in this situation; it's not by any means confined to people with a learning disability. I hope that's some comfort.



I want to scoot off somewhere

Q I need to use a mobility scooter and I'm currently considering holiday options. What is the likelihood of being able to hire a scooter at one of the popular holiday destinations in, say, Spain, Italy or France?

John McFee, by email

Andy Wright replies:

There is an ever-increasing number of mobility rental

shops abroad in lots of the most popular holiday destinations, many run by expatriates, that offer scooter and wheelchair rental, as well as a variety of mobility aids to assist you while on holiday. The best advice is to book your travel arrangements with a disability holiday specialist, who would be happy to make all the arrangements for equipment rental locally, on your behalf.

→ If you have a question for our panel

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pete's place

Myth of the life of Riley



Hidden in the Government's proposals for cutting disability benefits is that old assumption that too many people are milking the system. **Peter White** debunks the faulty logic of a common prejudice

With the regularity of cuckoos in spring, the search for disabled scroungers milking the system and needing to be "rooted out" appears on the agenda of all new governments.

It doesn't matter that there's no evidence for it. Each time civil servants charged with studying fraud relating to disability in the social security system are

asked about it, they say it's tiny: statistically almost insignificant.

So why does this hare start up whenever a new government comes to power? Part of it, of course, is that the money paid to people in respect of disability is high compared with what was paid in the past. And that's because until the 1970s, even after 30 years of the welfare state, virtually no provision was made for the

extra costs incurred due to disability. Funding was a humane response to a blatant injustice, entered into by both major political parties. Mobility Allowance, Attendance Allowance and Disability Living Allowance were all introduced as a considered response to properly costed needs, as were benefits such as invalidity and incapacity benefit. Of course the figures have gone up: they

were rising from zero, in a group depending till then on the most basic levels of subsistence.

People forget that you don't get benefits without medical intervention: you don't just go along and say "I feel a bit disabled today" and get handed the money!

Attempts have been made over the years to discredit GPs by alleging they hand out sick-notes like confetti. Some may have done in unemployment hotspots in the 80s and 90s, but it can't explain the persistently high figures that have resisted attempts by both parties to bring them down.

What does explain it are high levels of stress, and disabilities that involve high levels of intermittent pain, in a harsh employment climate. It's not something people readily understand unless they've experienced it, and it's interesting that those who persistently dismiss it – politicians – are those whose main fear of losing their job is triggered by fiddling their expenses.

We should expose them to a cycle of being tested for work fitness, telling them they hadn't qualified for the benefits they'd been promised, and sending them on a series of inappropriate job interviews, only to be constantly rejected! That's the reality for many people these days.



Wheelchair Drivers

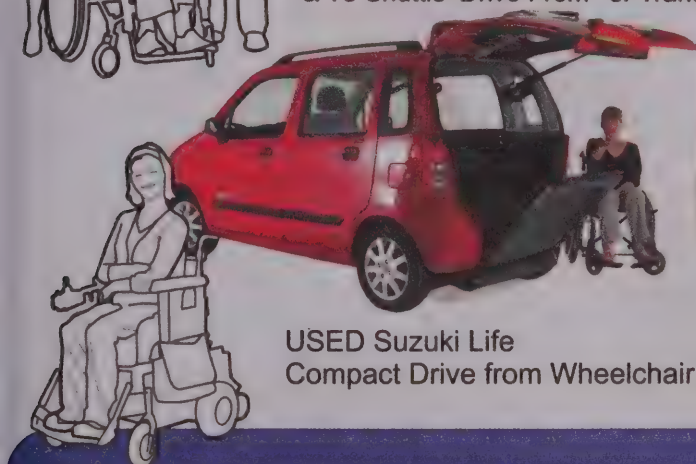
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guestcolumn

Charities: put up or shut up



With disabled people and our benefits under attack, says **Professor Peter Beresford**, it's now time for charities to take the Government on in support of and alliance with those they purport to represent

The coalition Government has made great play of the noxious term "vulnerable people" in setting out its policy stall. "Vulnerable people", much trumpeted, are identified as one of its key concerns.

So when it talks about making swingeing cuts in public expenditure to meet the current financial crisis, it adds that one group whom it will look after at all costs, and whose "front-line" services it will go the extra mile to safeguard, are "vulnerable people": notably, older people, disabled people and others on low income.

Yet it's on such "vulnerable people" that the hammer is set most clearly to fall. Access to disability benefits like Disability Living Allowance and Employment and

Support Allowance is going to be even more fiercely policed, with ever-tightening medical checks creating a new UK

equivalent of the Stasi. By throwing people off

disability benefits big-time, welfare reform offers politicians a multi-billion-pound income-generation scheme.

In this way it neatly kills two birds with one stone, attacking the deficit and "dependency culture" at the same

time. Or as disabled people's and service users' organisations are increasingly putting it, probably seeing off increasing numbers of disabled people through increasing poverty, social isolation and despair.

For the first time in modern political history, including even Mrs Thatcher's period in office,

there is a consensus across all three main political parties about the desirability of attacking disabled people on benefits.

What this new policy thrust also sadly highlights is that benefits are still the key policy for disabled people, despite years of equality and anti-discrimination legislation.

This isn't just a crisis for disabled people, though: it's also crunch time for the big old disability charities that work for disabled people but aren't in fact run by disabled people. Many such

organisations have tried to

restyle themselves as disabled people's organisations (DPOs) or user-led groups. Will they now come out determinedly

to support disabled people's rights and needs at this time of crisis, or will they be more concerned with their role as service providers and contractors, and with their

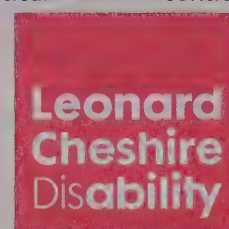
own organisational interests, as so often has seemed to be the case?

It won't be enough just to sit on the fence and

offer general platitudes about social justice and inclusion. Some very determined campaigning and lobbying is going to be needed. The charities must make the Government feel

uncomfortable about its regressive policy. That in turn will mean the Government feeling much less comfortable with them.

It really is time for the charities to take the lead they've often taken from DPOs. They must put up or shut up. The assault on disabled people's rights is not an issue they can now duck or be allowed to duck.



→ Have your say

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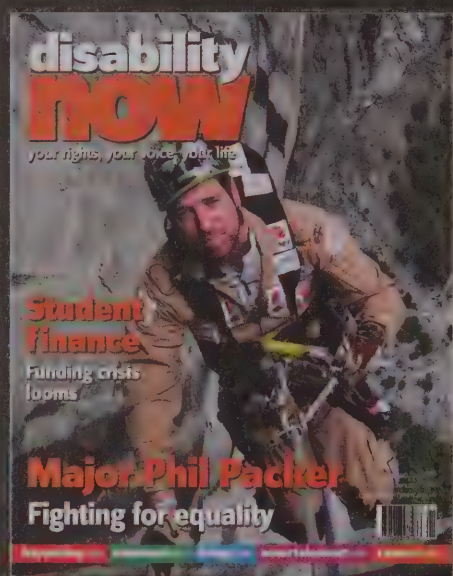


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upclose&personal

Choosing to sit tight

Having created a strong identity and personality as a wheelchair-user, **Mik Scarlet** woke up one day to find he could go back to walking



In 2003 I had to undergo a spinal reconstruction. By this time I had been a full-time wheelchair-user for 22 years, and had built the kind of life most able-bodied types dream of. I toured in bands, was a TV presenter and journalist, an

actor and, if I'm truthful, a bit of a media whore. I had a fantastic fiancée who I loved and loved me back. In fact, the only bit of my life that was a bit crap at that time was the amount of pain I was in as my spine collapsed and the amount

of strong painkilling medication I had to take for it. It was to stop this pain that I initially agreed to undergo major surgery.

When I came round after 15 hours, I immediately felt something was wrong. It was when I sat up for the first time I realised what it was. When my feet touched the floor I actually could feel it. I had been able to feel the bed sheets and breezes. I also found that I had loads of movement coming back too.

When I came round after 15 hours, I immediately felt something was wrong. It was when I sat up for the first time I realised what it was. When my feet touched the floor I actually could feel it

The medical staff were overjoyed. Not many spinal surgeons can claim to have cured a paraplegic! However, even though my nerves were working better now, I did have other issues. My right hip had dislocated years back, and over time it wore

away. So if I was to walk I would need a false hip, that could have been fitted after I had laid in hospital for two months with an open wound, having my muscles and nerves stretched. Hmm. Then it became plain that my bone density wasn't up to walking, so I might also need a replacement knee and then ankle. Double hmm. Then I was told how long the physio might take... between two to four years.

Now, as I said, I really liked my life, but I was also very proud of being disabled (and still am!). I have never held any desire to be more like the able-bodied, and actually feel that becoming a wheelchair-user allowed me to fulfill my dreams and ambitions. My entire identity was as a wheelchair-user. Waking up one day to find that I had been cured was not the joyous event everyone else seemed to think it was. As the "walk again" pressure grew, my resolve against further painful operations and years of physio grew along with it. I can still remember the face of my surgeon when I told him that I liked being disabled, and would not be going ahead.

So now here I am, probably the first person to have been cured of paraplegia, and to decide to stay in a wheelchair. Because I am disabled, a wheelchair-user and I am proud of it.

Clare's loving her legs

Clare Smith featured on *How to Look Good Naked*'s disability special, but before the programme aired, her husband was killed. Amazingly, Clare's Gok-inspired confidence is helping her cope with her loss. **Lara Masters** finds out about the transformational impact a makeover has had on her life.

Lincolnshire locals Clare Smith, 45, and husband Neil always loved bikes: "We met on a blind date at a motorbike club run and were married six weeks later. We always had a bike or three and I still rode pillion with him after I had my leg off."

This may seem surprising, as it was a motorbike accident that led to Clare's amputation. "I broke my left foot but there were complications which the doctors didn't take any notice of. A blood clot formed and I got Reflex Sympathetic Dystrophy which is an excessive pain disorder. I had an ulcer all over my leg; it was like a piece of rotting meat. It was four years before I had a through-the-knee amputation. I was very angry as they could have saved more of my leg if they'd only paid attention."

For Clare, who has two daughters and a son with Neil, losing her leg also meant losing much of her self-esteem. "Before the accident I was a fit, active 36-year-old. I wore trendy, outrageous, daring clothes and felt my legs were my best assets, but for the last eight years, with only the use of my right leg and crutches, I've hidden in big, dark, dowdy clothes so I wouldn't be noticed."

"It was Neil who put me up for Gok Wan's show. He knew how sad and under-confident I'd become, plus he knew I love a challenge and always try to champion disability, as our son Thomas, who's 16, has cerebral palsy, epilepsy and autism and finds life very hard."

How to Look Good Naked turned out to be much more than a make-over; it was a pivotal moment in Clare's life.

TIM KEETON / IMPACT IMAGES



“I would recommend a style overhaul to anyone, male or female, disabled or not. It’s not only about discovering how to dress yourself in the best way possible, it’s also a very emotional experience; you learn so much about who you are”

“I believe taking part in the show and regaining my confidence has helped me somehow survive the sudden death of my husband who was killed in a road accident just two weeks after filming. We’d been married just over 21 years.

“Neil had been in the RAF for 22 years and did a lot for charity. I’m now involved with BLESMA (British Limbless Ex-Service Men’s Association) and I’m hoping to do some flying and work with Afghanistan amputees to highlight the poor quality prosthetics we get from the NHS. I also want to make the public more aware of disability and encourage more tolerance and understanding.”

Clare is already succeeding in creating awareness: after seeing the show, motorbike clothing company Frank Thomas asked her to model for their “Real Riders” campaign, which uses genuine bike-lovers in its advertising.

Even more remarkable is that after her husband’s death, Clare is determined to continue his legacy and fight for the rights of disabled people. But it was with Neil’s encouragement that Clare found strength through self-acceptance and began to see herself as he saw her.


After courageously facing her insecurities on national TV and rediscovering the confident, sexy woman she once was, Clare cannot fail to get attention and make a valuable difference – especially in those *short shorts*! ■



“I’d recommend a style overhaul to anyone, male or female, disabled or not. It’s not only about discovering how to dress yourself in the best way possible, it’s also a very emotional experience; you learn so much about who you are.

“Through the show, I was given a very real-looking cosmetic leg from Dorset Orthopaedic which makes me feel like a sexy woman again. I am so much happier with myself now, both with the leg on and also without it.

“I feel stronger, more confident and more complete in who I am. Now I dress in shorts, high heels and mini-dresses – all sexy, flirty, ‘Wow!’ things – to make people look at me. My favourite piece of clothing is a pair of *short shorts* and my favourite body part is my legs!

A photograph of a woman sitting on a wooden bridge over a pond in a lush garden. The woman is in the foreground, sitting on the edge of the bridge, looking down. The pond is filled with lily pads and reflects the surrounding greenery. In the background, there are more trees and a small wooden structure. The title 'Chinese takeaway' is overlaid on the image in large, white, bold letters.

Chinese takeaway

A family connection enabled **Cathy Reay** (pictured above) to visit a city which is not normally one of China's regular tourist destinations. She enjoyed sumptuous Chinese banquets, beautiful gardens and warm hospitality. But she also found a country which mixes rapid development and westernisation with older monuments, superstitions and attitudes

Although my brother has lived in China for the best part of a decade, I've always found reasons not to visit: "But it's not as cool as Japan! Not as beautiful as India! Not as tropical as Thailand!"

Naturally, my indignation and stubbornness were both completely unfounded. Not only is China the most beautiful country I could ever dream

of, there are enough trendy, modern, tropical, hilly, flat, colourful, wild, skyscraper-filled places for an entire lifetime of sightseeing.

My brother lives in the small city of Suzhou, a couple of hours north of the overwhelming metropolis of Shanghai. Unknown to me before our arrival, this unfortunately meant that, after 19 hours on a plane, we then had to

board a cramped, stinky bus for another three hours. A cramped, stinky bus with no toilet. This, I later discovered, set a precedent for an alarmingly toilet-free district. In fact, where public toilets did exist (generally in the tourist areas, which we avoided anyway) they were simply holes in the ground. Owing partly to my disability, and perhaps also



KEITH REAY



CATHY REAY

Small boats take travellers on a scenic journey up and downstream on the Yangtze

because I really haven't practised enough yoga, it was difficult to get used to. Yes, the very first access problem I had with this holiday was the lack of places to pee; let's just say I'm not a very gifted squatter.

Suzhou turned out to serve a transitional purpose, its two million inhabitants bridging the gap between what I previously understood to mean "busy" and the reality of Shanghai's frantic 20 million plus population. Sandwiching a small section of China's longest river, the Yangtze, the city's dazzling and genuinely interesting green spaces and stunning hilly

backdrop make for plenty to see and do. There's scarcely any tourist trade, which can be good in terms of crowds but bad in terms of being able to understand the language; if my brother hadn't been around we certainly would have had a lot of trouble going out to eat as it's often assumed you are so regular that you know what you want. Either that or the menu will be completely impossible to guess. Want an easy read version? Ha! Forget it.

The food itself, though, once you get it, is an absolute joy. Hot, steaming dim sum, huge bowls of noodle soup,

tasty honey-soaked fruit and all kinds of weird and wonderful fresh fish dishes are regular staples and all often for a quarter of the price you'd expect to pay in the UK. Most stuff is unfortunately still coated in monosodium glutamate, but is noticeably far less fatty than the buffet trays in the shabby-looking Chinese takeaway round the corner. I mastered chopsticks fairly well after a while, though not without a few spillages along the way, but the thing I found hard getting used to was eating everything at the same time. There's no starter, dessert or meat and two veg, dishes are brought out in the order





CATHY REAY

Above: A woman plays flute in one of Suzhou's gardens as part of a traditional Chinese opera performance. **Below:** The overwhelmingly tall city landscape of Shanghai



CATHY REAY

they're prepared, placed in the middle of the table and everyone digs in. I certainly learned how to eat a lot faster!

While we were in Suzhou we visited what felt like a hundred odd gardens, which was actually one of the best things to do. Each wildly different to the next, they featured huge, beautiful pagodas, monuments and temples with their own individual style, history and purpose. If you can ascend a pagoda or two it's well worth it as they often hold the best views of the city (no lifts though, obviously).

At night time the larger gardens are

often illuminated by fairy lights and some hold arts events. We saw a rather unusual opera where Chinese performers danced, sang, played and prayed through a series of short stories around eight very different subjects. I'm not sure whether it was just the language barrier that confused us there. Gardens and temples are great for those on a budget as they are normally free, though if you want to see an opera expect to pay around £8.

The gardens in Suzhou are very hard to get to if you don't recognise any symbols; in fact I expect this can be

broadened to any journey you want to take in less-westernised areas. Most people seem to take taxis due to their obscenely low price (a £1 minimum and £3 maximum charge in the city centre) and the fact that the city buses aren't very sensibly routed. Plus, of course, there is the accessibility issue and neither method of transport seemed equipped to solve that.

Near the end of our trip we went to Shanghai for a couple of days. The first startling difference I noticed was the sudden increase in price for everything; in Suzhou you pay a maximum of £3 for a taxi, or 10p for a bottle of water (good luck finding water that isn't carbonated though), in Shanghai you pay a minimum of £2.50 for a taxi or 90p for water. Of course it's all dependent on whether you know where to go to avoid the tourist prices, and shopkeepers will often sneak them up for foreigners (as they call us) if they can get away with it.

Everything in the city is magnified; roads are long and wide and tall buildings are constantly being extended skywards to accommodate for the number of workers. People are usually expected to use overpasses to get across busy roads, which can be tiring with all the stairs. We visited the World Financial Center, the third tallest building in the world, and used the first elevator we'd seen on our entire trip to travel to the top and appreciate the city view from up high. I also walked down Nanjing Road, a six mile long shopping street filled with (disappointingly western) brands and food outlets.

Back in Suzhou, we took a boat ride around the city and visited a Mandarin restaurant that looked like it had been taken straight from the Aladdin storyboard (still no fortune cookies in sight though). Many of my brother's friends' families took us to dinner

during our stay and insisted on paying for everything, which, we learned, was customary treatment for visitors. It seemed like once you are no longer a stranger, native people will naturally go out of their way to accommodate, help and, particularly, accompany a foreigner anywhere and everywhere. I grew to really appreciate the companionship I was so frequently offered.

I definitely noticed an absence of visibly disabled people during my trip. Though China is very rapidly evolving in light of its booming tourist trade and strong western influences, attitudes to disability are still very much rooted in the past. A Kingdom of Little People was recently opened in the province of Yunnan, northwest of Hong Kong, in which short-statured people are employed to entertain visitors with repertoires and performances akin to something from a 90s childhood trip to Butlins. Disabled people are segregated and, it seems, shooed away from the public eye. I didn't see a single disabled person in 15 days, which, when

compared to the 12 I saw in half that time in Germany, is very telling.

I was told to expect that people would stare, regardless of their age, and take pictures. That definitely happened, and was quite a shock, but it wasn't as negative an experience as people make out. I slowly realised that people were just genuinely curious and the upfront, no-nonsense approach to life meant that they saw nothing wrong in snapping a quick picture of someone. A class of schoolchildren passed by me one day, all staring, and then they came by again and again, until one had the courage to approach me. Instead of calling me a name or asking something about why I was short, she simply questioned why I was sunbathing because they all thought I shouldn't tarnish my "beautiful white skin". The rest of her class then formed a circle around me and started telling me they loved me.

My initial discomfort with attitudes like this made me realise how repressed British society is. Why don't we wander around holding our girlfriends' hands?

Or kiss people every time we meet them? While the political landscape in China may not be one I particularly agree with, its people are still going about their lives in a positive way. I met so many genuinely warm, happy faces that it rubbed off on me and I began greeting people with the same affection. When I eventually reached London again, with dozens of photos, email addresses and happy memories in my pocket, I was very sad to go back to quick gaze-averting hellos. ■

Tips

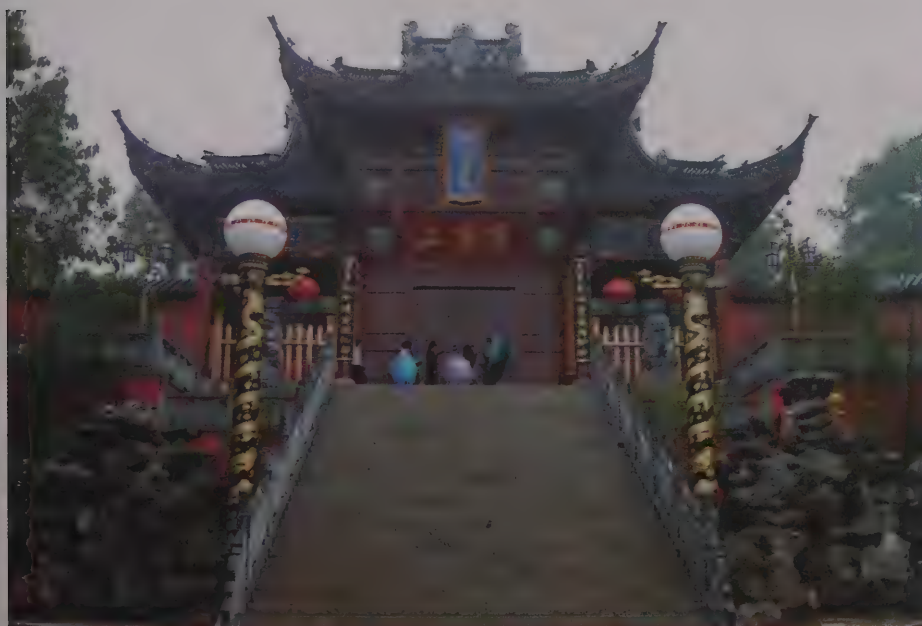
Visit a Chinese hot pot restaurant. A vat of thin soup is placed in the middle of the table and diners are expected to drop various raw ingredients in, wait while they cook, and fish them out eating directly from the pot. Hot and messy but very fun!

There are millions of temples, but a particularly impressive one can be found at the very top of Tiger Hill, which also plays host to amazing views of the Suzhou city landscape. Amazingly, it's accessible to wheelchairs if you can get someone to drive you up. Visit tourochina.com/sightarea/322/Tiger-Hill for more information.

Take toilet paper and hand sanitizer absolutely everywhere.

How to get there

Qatar Airways were the cheapest airline we found at around £400 for a return trip, though they rarely do direct flights. Suzhou is a 2½-hour bus ride from Shanghai Pudong airport but buses are rarely accessible, or a £30 cab journey. Visit qatarairways.com and travelguidechina.com for more information.



CATHY REAY

A temple, overlooking Suzhou, at the very top of Tiger Hill

Local knowledge. National disability expertise.

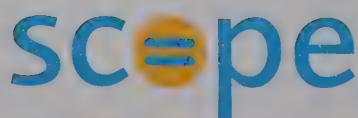
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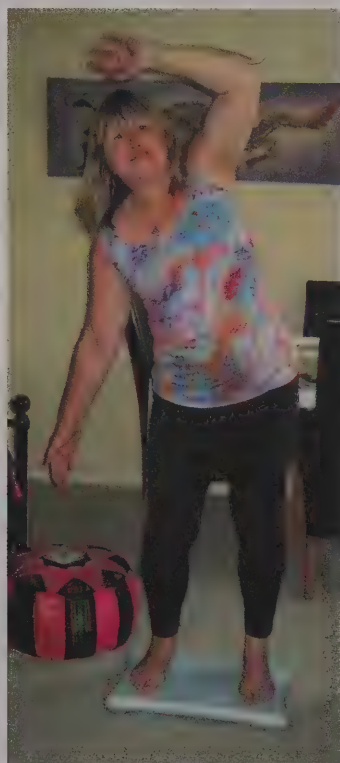
Keeping, getting or staying fit can sometimes be a grind. But **Gill Hamper** has found a way of turning that whole business into a game

Since being diagnosed with fibromyalgia a few years ago, my muscles, which used to be toned, are now weak and painful. As even the simplest action, such as walking or bending, can hurt, it is very tempting to rest all the time to avoid the pain. However, this lack of action makes them even weaker. It is a very vicious circle.

While I was at a Fibro support group meeting a few weeks ago, one of my friends said that she had been using the Nintendo Wii and found it very helpful, so I bought one to try it out.

It was easy to set up, all you do is find a channel for it on your TV, I use channel AV3, then attach the cables and plug everything in.

I started working with Wii Fit, a set of various sorts of exercise programmes and games. At the start of each session you enter your age, height and sex, and select an icon to represent you on the screen. You also need an extra accessory called a



Balance Board.

When this is set up, it is able to tell you your Body Mass Index (BMI), weight and centre of gravity every time you log in. I found this helpful as my balance is poor, and learning how to stand so my centre of gravity is correct, makes me aware of when I am lopsided.

When I first began to use it, my movements were very slow and so was my reaction time. I was also worried about overdoing it, and

being in pain either at the end of the session or the next day. Fortunately this did not happen, and I was able to use it again the next day.

I try to do it for 20 minutes a day, and already my muscles are working more effectively. Lifting a kettle of water no longer requires two hands, and now when I bend over to pick something up off the floor, I can often stand back up without holding on to anything.

Mixing fun with the benefits, I've also been playing games for which you don't need to use the Balance Board. My balance and co-ordination, which were a huge problem, have been helped a lot by the various games such as Penguin Slide and Snowball Fight. There are



games or exercises for every muscle group, but mainly I play the ones which also work on toning, balance, co-ordination and flexibility.

An added benefit of all this exercise is that I am losing weight, and the less I weigh and fitter I become the better I feel. The reason I am finding the Wii so effective is because of the games, which make it fun. Whereas 20 minutes of normal exercise can feel like forever, 20 minutes of playing games flies by.

INFORMATION

argos.co.uk: Wii Console + Wii Sports + Sports Resort + Wii Fit (incl. Balance Board) £229.99
Wii Fit Plus only (incl. Balance Board) £74.99

helen dolphin

TV advice isn't just the ticket



Beware the well-intentioned words of TV presenters, says **Helen Dolphin**. When it comes to parking and parking penalties, they don't always get it right

Like many drivers I have received the odd penalty charge notice (PCN) – or parking ticket as they are more colloquially known – in my time. Usually they were for stupid mistakes like forgetting to display my Blue Badge or parking for longer than I should have. However, not all PCNs are the same as different organisations enforce parking rules and this means your rights vary depending on who issued the ticket.

In most parts of the UK on-street parking is enforced by council-employed Civil Enforcement Officers who issue Penalty Charge Notices through the civil justice system. Some council car parks have parking attendants who can issue Penalty Charge Notices which you can



challenge in the same way as a PCN issued to a vehicle parked on the street. However, some other off-street car parks are managed by private companies and this is where it can become more complicated.

I had always presumed that whoever issued the ticket you either had to contest it or just pay up so when I was watching the BBC *Watchdog* TV programme recently I was surprised to hear the advice given out. This was basically

to "ignore parking tickets issued by private operators". This advice given out by a solicitor was endorsed by the presenters as "perfect" and "brilliant legal advice" and they even suggested that viewers made paper darts from their

tickets to see how far they would fly!

So is it OK to just flaunt parking rules in off-street privately run car parks without fear of redress?

Kelvin Reynolds, Director of Operations and Technical Services from the British Parking Association (BPA) says not. "Unfortunately *Watchdog* seemed to imply that it is perfectly acceptable for somebody to stay as long as they like in a private car park provided by a retailer for its customers and that these drivers can ignore any action taken by

the retailer. It is lawful for a landowner to manage his land and to seek compensation for breach of contract. The BPA is aware of many cases where our members have successfully pursued these claims through the courts and judgements have been made in favour of the operator."

If the advice from *Watchdog* was true and drivers could ignore any parking ticket issued to them it could end up being a nightmare for Blue Badge holders. We all know how

frustrating it is to find all the disabled bays taken by non-disabled people and if tickets can be completely ignored there would be nothing to stop bay abusers. Also, if all tickets are ignored in the longer term, it would probably lead to a greater number of companies using clamping as an enforcement technique as this is far harder for motorists to ignore! Although valid Blue Badge holders shouldn't be clamped, if you forget to display your badge then obviously this exemption

won't apply. Coming back to a clamped car is a far more physical and immediate punishment for contravention than a parking ticket and if you are on your own and it's late at night it could be really frightening. It is also much easier to appeal a ticket than try to escape paying to have a clamp removed.

So although it's tempting to ignore any parking tickets in the future I'm not convinced by *Watchdog's* advice and I, like most other motorists, will be paying or appealing my tickets.

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By Paul Carter



ACTION IMAGES / JASON CAIRNDUFF LIVEPIC

Woods joins Weir in Delhi decision

Wheelchair athlete Shelly Woods has become the latest track and field athlete to withdraw from the Commonwealth Games.

Paralympic silver medalist Woods has made the decision not to compete at the four-yearly event taking place in Delhi this October, instead opting to focus her attention on January's International Paralympic Committee (IPC) World Championships.

Woods said that although the decision was a difficult one, it was "a question of prioritising".

She said: "I have done all the qualifying times for the World Championships and I would rather be training for them because they are more important."

"I would love to go to the Commonwealth Games but

they come at the wrong time for my schedule.

"I have qualified for the 1500m, the 5000m and the marathon in the World Championships. I have also qualified for the 800 metres but I doubt I will compete in that."

Several other athletes are due to face a similar decision in the coming weeks, as the Commonwealth Games fall

in the middle of what athletes refer to as "heavy training," making it difficult to compete in both events.

Woods joins double Paralympic champion David Weir in not making the trip to India. Weir announced he would not be competing last month after voicing safety concerns following recent terrorist attacks.

"I've got a family to think

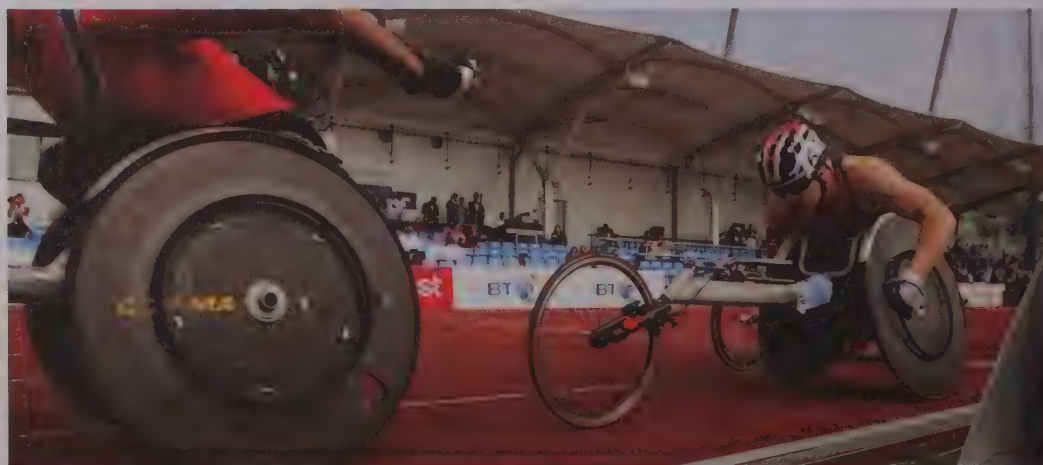
about and I genuinely don't feel safe going to Delhi and not even a small part of me thinks it's a good idea to be there," he said.

"I'm sure when the Games are on in October, I'll be gutted to miss the racing. But there was another bomb scare there for the cricketers the other day and I just don't fancy that."

As well as training for the World Championships, Woods will now also set her focus on the upcoming New York Marathon and the Great North Run.

Woods has come second three times in the New York 26-miler, and is determined to go one better in 2010.

"I have always said I want to win the New York Marathon and I have not managed it yet. Last year I missed the Great North Run, one of my favourites, because I was in the Berlin Marathon and I wasn't pleased when someone took my course record!"



ACTION IMAGES / LEE SMITH LIVEPIC

IPC says Paralympics on track

The global governing body of the Paralympic movement has given a cautious welcome to the progress being made on preparations for the Games in London in 2012.

Officials from the International Paralympic Committee (IPC) were in the capital as part of the International Olympic Committee (IOC) Co-ordination Commission, which meets regularly to assess developments in all aspects of the Games.

Chief Executive of the IPC, Xavier Gonzalez, and Paralympic Games senior manager Thanos Kostopoulos also came to London to cast their eye over progress in areas including transport, planning and the development of accessible accommodation for Paralympic athletes.

Branding and marketing topics were also discussed including a Paralympic campaign plan.

A delegation also

conducted a site visit of the new aquatics centre, where it was confirmed that the swimming programme for the 2012 Paralympics will extend to ten days for the first time.

Patrick Jarvis, IPC Governing Board and IOC Co-ordination Commission member, said: "We had very productive meetings and are generally pleased with the progress in several areas. With Sainsbury's as an exclusive Paralympic sponsor for example,

LOCOG has had significant development around the Paralympic Games."

However, he sounded a note of caution.

"Although numerous Games-related technical challenges still need to be addressed, I have complete faith that these and other issues will be navigated by the Organising Committee in collaboration with the IPC, promising a most spectacular Paralympic Games in 2012," he said.

The Commission will visit London again in November to assess progress further.

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entertainmentnow

THEATRE



Drama and darkness: Sight and sound of deafblind theatre

Not By Bread Alone
Nalaga'at theatre
company, Arts Depot,
London

Not By Bread Alone is a new production from the world's only deafblind theatre company from the Nalaga'at Centre at the Jaffa Port in Tel Aviv.

As the audience took their seats at the Arts Depot in North Finchley, the cast of 11 were already on stage kneading dough in a warmly sepia-lit, wood and brick bakery set. The ensemble took turns to introduce

themselves and talk about and act out their memories and dreams as "we do not live by bread alone".

It's a dynamic production, with lots of movement around the stage, mime, music and dance. Rehearsals lasted for two years as the cast learned the stage directions and cues.

There is some sadness of wishing that things could be different – yearning for lost senses and dreams of sight or hearing restored – but the emphasis is largely

on celebration and fun with a dash of education for the audience. Bat-Shiva Ravenseri dreams of seeing her son's face when he returns from the army but more is made of her dream of getting an appointment with a celebrity hairdresser.

There is some Chaplin-like miming of sandwich eating from Marc Yarosky and some comic exchanges between characters. Shoshana Segal gets exasperated with Genia Shtasky's one-upmanship, everything Russian is better,

even the rain: "The rain in Israel would not even get you wet!"

There is no overt mention of the Israeli-Palestinian conflict. Soldiers are mentioned twice in passing during the play and at the end the Artistic Director, Adina Tal, said that at Nalaga'at "Jews, Muslims and Christians work together".

There is a triumphant ending to the play: a Jewish wedding. The audience gets to shout "Mazel Tov!" and is invited onstage to share the bread that has been baking during the performance and meet the performers.

The interactive Nalaga'at experience doesn't end here. They've also exported Café Kappish staffed by deaf waiters and The Blackout Bar with blind waiters in complete darkness.

Kelly Mullan

To complement the performances *Sense*, the deafblind association, has created a Touching Art exhibition at the Arts Depot. *Sense* helped bring Nalaga'at to the UK and is planning future deafblind arts events to be announced. sense.org.uk

BOOK

A life and love of travel

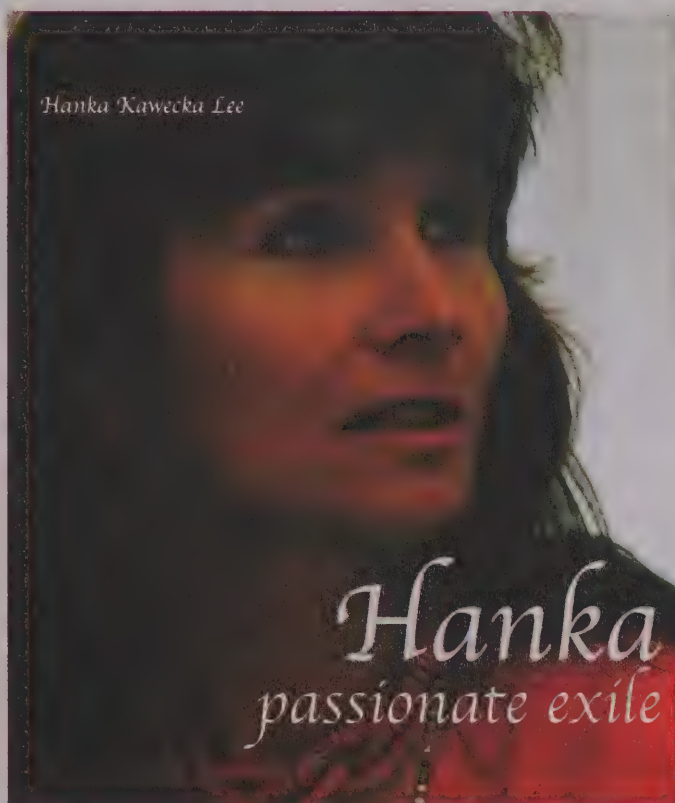
Hanka: *Passionate Exile* Hanka Kawecka Lee

Passionate Exile is a beautiful coffee table book, rich in colourful, exotic photography and fascinating, evocative travel journalism.

This collection of selected travel articles by Hanka Kawecka Lee was compiled and published posthumously, each article individually and lovingly prefaced by her husband Michael. Articles that originally appeared in the UK's *Sunday Observer* and the altogether more exotic *Jakarta Post* and *Dziennik Polski*, are brought together in vivid relief with lush imagery.

Hanka, an environmentalist originating from Poland, lived with multiple sclerosis (MS) for the latter 12 years of her life. Her debilitating condition, however, is a mere footnote to the life of a charismatic and compassionate humanitarian.

Hanka's writing breathes vitality into the colourful characters and cultural traditions to which she bore witness whilst journeying across Africa, Asia and



Eastern Europe. She recounts conversations overheard between a shop assistant and her patron in a newly-privatised Warsaw marketplace grocery, in sharp contrast to stark but sympathetic accounts of the rituals of the Maasai tribe, making situations that are alien to most of us seem both familiar and fascinating. If MS hampered her enjoyment of life, or hindered her travels, Hanka

notably in the curiously titled "My hospital, my home". In this tribute to the (aptly-named?) Royal Free, Hanka describes the London hospital as a "safe haven" which afforded her the time to reflect on her adventures, although her description of some nursing staff as "careless and cruel" perhaps belies her true journey though the NHS system of care.

As this collection was not compiled by Hanka herself I wonder whether she would have chosen to include an article about her declining health as the afterword to a set of accounts otherwise so rich in joy and wonder, and which to me seems a sad adjunct to the chronicle of an otherwise exhilarating life.

Julie Howell

• *Hanka Passionate Exile*; Hanka Kawecka Lee; Published 17 September 2010; Amber & Turquoise Books; amberandturquoise.com

chose not to reveal it to us through her writing.

Hanka was 53 when she was diagnosed with MS, and while some of the writings in this collection date back to the 1960s, many articles were penned post-diagnosis. Yet MS is explicitly mentioned in only the final few articles, most

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webwatch

Another brick in the wall

Graffiti is not usually recommended as a legal means of self-expression or stress relief, but **Kelly Mullan** has found an online resource where it is positively encouraged as therapy

Bricks as a means of self-expression are no longer just for riots! Members of Big White Wall, an online mental-wellbeing service, can draw on bricks and post them on a wall, to garner emotional support from an online community.

The drawing tools are easy and fun to use, and the process is cathartic. I tried out Big White Wall at a time of stress and found it a helpful release. The peer-support aspect took me by surprise: you don't expect kind, insightful comments from strangers online.

Jenny Hyatt, founder of Big White Wall, got the idea during a breakdown when she came across a community art project encouraging people to express themselves using graffiti on the walls of a condemned building.

She says: "Big White Wall is based on the notion of community: people having a group around them to help them work through difficult

episodes in their lives. It reduces social isolation and we found that 72 per cent of people are sharing a problem for the first time.

"We charge for the service because it does have people working and moderating it 24/7. We place a lot of emphasis on people being safe and look out for bullying or seductive behaviour. I set up Big White Wall when I was in a fragile state so I know the importance of feeling safe when you're vulnerable.

"We're learning from our community how to be more

accessible and Big White Wall meets WC3 accessibility standards. A member of the community with a visual impairment gave us feedback so we've increased the size of the avatars and used a new easier-to-read font."

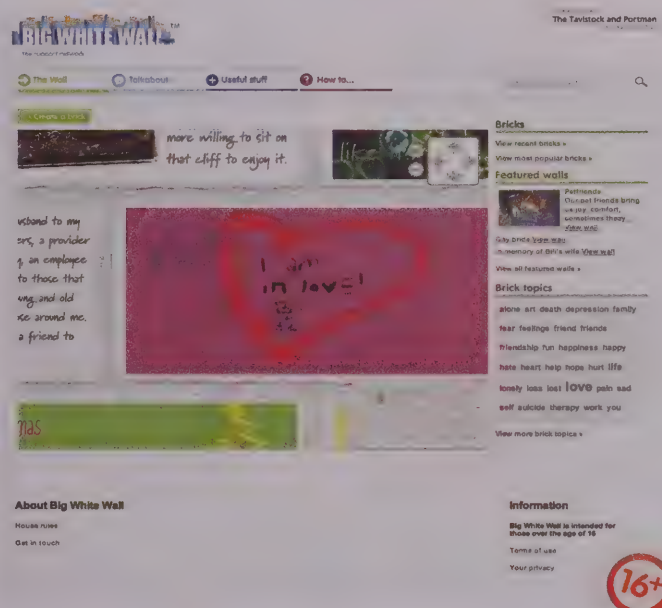
The NHS has seen potential in the idea and 12 Primary Care Trusts (PCTs) are offering a free year's membership to the site from this month. Just type

in your postcode to see if it's free in your area. If not, there's a charge of £2.00 per week.

"PCTs are interested because it saves money, it lets people access support quickly, it's less stigmatised, and insomniacs like me can access it from home at 4.00 in the morning," says Jenny Hyatt. "I've known at least two people who've killed themselves while on waiting lists to get psychological support. Big White Wall could unblock a health service set up primarily to deal with physical health: we're involved in policy debate on wellbeing and mental health."

Used in this way by the NHS, Big White Wall could be an innovative stopgap for people on waiting lists and could even help some people resolve their problems to the extent that they need no further intervention. Big White Wall should be seen as a useful adjunct to mental health services, however, and not another excuse to cut them further.

• bigwhitewall.com



→ Have your say

- write to us **Disability Now**, 6 Market Road, London N7 9PW
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- phone us 020 7619 7323

worklife

Mind the gap year

Like many people at the end of their schooling, **Emily Steward** wanted to take time out from education. She wound up working with children in the slums of Mbale in Uganda



I'd heard of the charity Jenga through my church but I thought it would be impossible for someone with such a physical impairment to go to Uganda. My friend Amy and I contacted the charity director and talked it over with him; he said he'd love to have two young people helping out, and didn't see my impairment as a problem. And my friend and I ended up in Mbale.

In the mornings Amy and I would be left with 100 plus young kids to look after in kids' club. We would play games like cat and mouse with them; it was important

to do things that let them just be children because at home they were learning so much responsibility (looking after siblings, cleaning, etc) and having to grow up so quickly. I couldn't always run around with them, especially in the heat, so I'd often sit back with a few girls and braid their hair, stuff like that. We also taught them basic things like personal hygiene.

Then some afternoons we'd work with kids from around 11-19 years, mentoring them and encouraging them to go to school. It's not easy to get an education out there; it

costs a lot so it's important for the kids to go to classes. We'd help them with homework too.

The Ugandan attitude to my disability was really interesting. They had the

idea that Westerners were invincible. So when they saw I had a crutch, that I had trouble walking, they were pretty mystified. But then once they were over it they were just so kind and helpful; kids would grab my hand all the time and help me walk through flatter routes through the slums.

I went to a nearby hospital called Cure in Uganda which specialised in treating children with spina bifida, to speak to patients. It was so humbling to be able to show them that people with spina bifida can live to 20 and travel to other countries. The kids felt they could ask me a lot of questions they'd never dared approach with doctors.

• For more information on Jenga and their community development programmes visit jengauganda.org
• Emily Steward was talking to Cathy Reay

EMILY STEWARD: CAREER PATH

- July 2008 – left secondary school with A-Levels in Biology, Religious Studies and Politics and an AS Level in Chemistry
- August 2008 – January 2009 – worked in a local shop to raise money for travelling abroad
- February 2009 – May 2009 – went to Mbale,

Uganda to work on Jenga's community development outreach programme

- June 2009 – had surgery to realign foot with three months recovery
- September 2009 – started a four year Speech Science course at University College London

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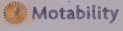



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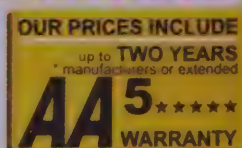
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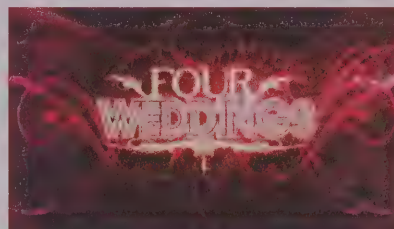
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DISABILITY SEMINAR

Inclusion London

Promoting Equality For London's Deaf and Disabled People

Inclusion London are pleased to announce:

Disability in the Equality Act:

What the Equality Act 2010 means for Deaf and disabled people and public authorities

A half day seminar, on 23rd of September on London's Southbank, presented by Caroline Gooding and Natalie Salmon (both formerly with the Disability Rights Commission)

There has been a great deal of concern about what the Equality Act might mean for Deaf and disabled people. This seminar provides the opportunity to look with experts at the practical effect of these changes

More details of the event are available on the Inclusion London Website at: <http://www.inclusionlondon.co.uk/>

If you would like to register your interest in the event please email: Libby.Oakley@inclusionlondon.co.uk

Liberty

Festival 2010

Saturday 4 September 2010
13:00–17:00, Trafalgar Square

Come and celebrate the contribution of Deaf and disabled people to London's culture.

This year's festival features zones for: Sport and Arts, Aerial and Circus, Street Arts, Music, Children's Area, and Cabaret and Comedy.

Liberty is friendly and accessible and welcomes people of all ages.

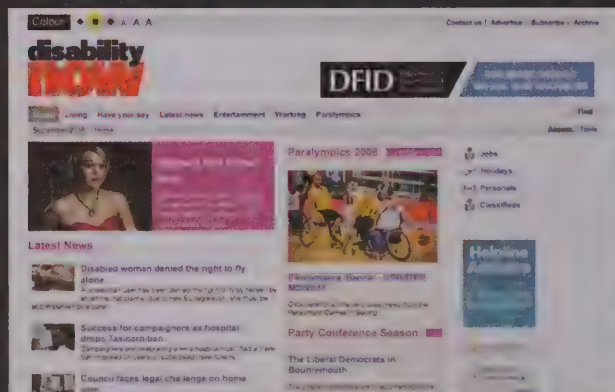
www.london.gov.uk/liberty

Painting of John Harris, Discus Paralympic Gold Medalist 1984
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MAYOR OF LONDON



disability now



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www.disabilitynow.org.uk

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RECRUITMENT



Participation Research Project Worker

£31,148 (fulltime NJC scale 2009/10 including ILW)

(JNC scale: PO33 pro rata 10 days per month (17 ½ hrs per week))

The Alliance for Inclusive Education, a national campaigning and information sharing network, is recruiting for its work within the Developing the Participation of Disabled Children and Young People project. This is a three year research project that will explore the most effective ways of enabling the participation of disabled children and young people in the development of services. Funded by the National Lottery through Big Lottery Fund, the project is being led by a consortium of the Alliance for Inclusive Education (ALLFIE), The Council for Disabled Children (CDC), the Children's Society and NCB.

We are looking for a Participation Research Project Worker to recruit and support a group of young disabled people to be involved in the delivery of the project as researchers and advisors.

We would particularly welcome applications from disabled people to be a part of ALLFIE's dynamic team.

If you would like to be part of this exciting new work please contact: Tara Flood at the Alliance for Inclusive Education – info@allfie.org.uk or Tel: 0207737 6030

Closing Date: 13th August 2010

Interviews: week beginning

23rd August 2010



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DN DEADLINE - September 2010 published 31 August.
Classified deadlines: Booking: 9 August. Copy: 11 August.

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backlash



Carry on camping Carter

As someone who used to think that camping was what Graham Norton and Julian Clary did on TV, **Paul Carter** was quite surprised by the real thing

I'm not, as you've probably gathered by now, the outdoor type. I'm far too fond of my creature comforts like electricity, the internet and not catching hypothermia to usually consider getting back to nature.

However, when I was offered the opportunity to go on a "camping and activity weekend", I had to reassess my view.

My only previous camping experience had been at music festivals, and that's less "sleeping under canvas", and more "passing out in a botulism-ridden bog", so when me and my trusty assistant Claire made the long trip down to Somerset, I have to admit to being more than apprehensive.

We were staying at a site on Exmoor, which doesn't sound like a suitable name for a picturesque holiday destination. Whenever I hear it I always think of misty wastelands out of a Tolkien novel. ("You're going to Exmoor, you say? Take this enchanted scabbard, there be goblins there.")

Not being an experienced camper, surprisingly enough, most of my stuff was begged,



“My previous camping experience had been at music festivals, and that's less 'sleeping under canvas', and more 'passing out in a botulism-ridden bog'”

stolen and borrowed. Even the tent was a loan. With that in mind, perhaps we should have checked the size of it before we left really, as neither of us were quite expecting a tent so gargantuan it looked like it needed planning permission to put up. Seriously, I thought we were going to need to dig foundations for the thing. It turns out enormo-tent had six different doors. Six! What kind of tent needs two doors per resident? We duly dubbed one of them the fire escape.

I'm quite glad I was with a friend when it came to assembling the damn thing.

Although I'm not sure she was as happy that I was as much assistance in putting the thing up as, well, a bloke with no hands would be in putting up a small house.

Add to that the fact it was dark, and I'd been drinking, I'm not sure we did it right. There were bits hanging out that probably shouldn't have been and things missing. And that was just me. Still, despite its ramshackle appearance, we hoped for the best, and thankfully enormo-tent was sturdy enough to stay up.

The highlight of the trip though was the aforementioned "activities", another word that usually

fills me with dread as I associate it with school trips to some centre or other, where I'd end up being strapped into some preposterous harness/medieval castration device, winched down a wall and told I was "abseiling".

As it turned out, I needn't have worried. I was actually taken out sailing and fishing by some quite wonderful volunteers who, against my better judgement, got me out on the water. I actually ended up rather enjoying it, who'd have thought? Who knows, maybe I am cut out for this outdoor business after all. I said maybe.

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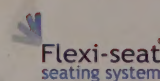
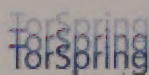
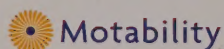
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